Lifestyle intervention for older adults in rehabilitation after stroke:

Development, implementation and evaluation

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‘Man - a being in search of meaning.’

Plato, *Plátōn*, Greek philosopher (ca.427-347 BC)

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December 2011, Anne Lund

List of papers

I. Lund A, Engelsrud G. 'I am not that old' : inter-personal experiences of thriving and threats at a senior centre. *Ageing & Society* 28, 2008, 675–692.

II. Lund A, Michelet M, Kjeken I, Wyller TB, Sveen U. Development of a person-centred lifestyle intervention for older adults following a stroke or transient ischaemic attack. *Scandinavian Journal of Occupational Therapy.* 2011; *Early online (doi:10.3109/11038128.2011.603353).*

III. Lund A, Mangset M, Wyller TB, Sveen U. 'Occupational threats' and reconstructions of occupational balance following stroke *(submitted).*

IV. Lund A, Michelet M, Sandvik L, Wyller TB, Sveen U. A lifestyle intervention as supplement to a physical activity programme in rehabilitation after stroke: a randomized controlled trial. *Clinical Rehabilitation 2011; Early online (doi:10.1177/0269215511429473).*

Summary

With the evolution of acute stroke treatment and better prevention of cardioembolic stroke, the case fatality rate has decreased and milder deficits are becoming relatively more prevalent. A paradoxical effect of this positive trend may be that less attention is given to rehabilitation, since many stroke survivors appear to be independent in basic functioning on discharge from hospital. However, older adults with stroke often experience anxiety, depression, lack of meaningful activities and restrictions in social participation within their daily lives for many years after the incidence. Almost half of the stroke survivors report unmet needs including mobility, falls, incontinence, fatigue, and emotional well-being up to five years after stroke.

Current practices of rehabilitation after stroke mainly focus on individual interventions for the first six months after stroke. There is an urgent need for the development and evaluation of long-term interventions aiming at promotion of well-being, activity and social participation after stroke. Also there is a paucity in the knowledge of how services offered at local senior centres can promote social participation and prevent social isolation for older adults.

The aims of this study:
The overall aim was to develop, implement and evaluate a lifestyle intervention for older adults conducted at senior centres after stroke.
The specific aims were to:
1) investigate older adults' inter-personal experiences of attending a senior centre (paper I).
2) explore older adults' occupational needs and issues of importance after stroke by applying the Canadian Occupational Performance Measure (COPM) (paper II).
3) describe the development of a group based person-centred lifestyle intervention for older adults after stroke (paper II).
4) explore how older adults experienced occupations in their lives following a stroke, analyzed in an occupational justice framework (paper III).
5) evaluate the effectiveness of a group based person-centred lifestyle intervention on well-being, occupation and social participation for older adults after stroke (paper IV).
6) compare well-being and social participation among the sample in our study with the general Norwegian population by using the Short Form Questionnaire -36 (SF-36) (paper IV).

Materials and methods:
The participants in paper I were drawn from registered users and volunteers (n= 636) who visited the senior centre more than twice a year.

The papers II, III and IV address 204 patients (and sub-groups) with stroke from six hospitals in two municipalities in Norway who were consecutively included from June 2007 until December 2009. Data were collected by means of participant observation, semi-structured individual interviews (COPM) and focus group interviews. A randomized controlled trial was performed to study the effectiveness of a weekly group-based lifestyle intervention as supplement to a physical activity programme. Both programmes started three months after stroke and were provided weekly for nine months. Qualitative, quantitative and interpretive analyses were applied.

Main results:
Older adults' experiences of attending a senior centre are diverse and continuously developed, contested and negotiated. Many users experienced a tension between a 'sense of thriving ', which the senior centre's activity and social opportunities provided, and a subtler 'sense of threat' in that attendance exposed them to the inevitability of personal ageing. The study

highlights the paradoxical situation that many old people face: they are encouraged to remain youthful and to embrace healthy and active ageing while, at the same time, they become older day by day. The senior centre provided social opportunities and seemed to have the potential of being an arena for rehabilitation after stroke.

There was a great variety of occupational needs after stroke in older adults. Occupational performance problems prioritized by 132 participants in the COPM interviews were related to active recreation, household and community management, mobility, and socialization. These occupational issues were addressed in the lifestyle group interventions held in five different senior centres. New themes also emerged in line with the participants' choices such as: information on stroke and prevention of new strokes, outdoor mobility and transportation, "brain use" and memory. Involving the participants in developing the intervention in line with their choices and needs contributed to a great variety in the content demonstrated in this lifestyle intervention.

The focus group interviews of eight participants provided insight into the ambiguity of how they, in different ways, felt stroke as an occupational threat constructed as social exclusion, lack of dignity and control, but this at the same time, triggered their reconstructions of occupational balance by addressing enjoyable occupations in a variety of ways.

In the randomized controlled trial 204 stroke survivors were screened, 99 (49%) were randomized whereby 86 (87%) participants (mean (SD) age 77.0 (7.1) years) completed all assessments (39 in the intervention group and 47 in the control group). A group-based person-centred lifestyle intervention as supplement to a physical activity programme showed no statistically significant additional effect on well-being, occupation and social participation for older adults after stroke.

The participants with stroke showed lower scores at baseline on SF-36 compared to that of the general Norwegian population adjusted for gender and age. After nine months several of these differences disappeared, which illustrated that such improvements in health and well-being can be found in later phase after stroke. Interventions addressing ability to get out out regularly and meeting with peers may be sufficient in the long-term rehabilitation after stroke to enhance well-being, occupation and social participation. This study highlights challenges related to develop, implement and evaluate complex psychosocial interventions.

Clinical implications

- A lifestyle group intervention as a supplement to physical activity group showed no additional effect on well-being, occupation and social participation for older adults after stroke.

- The participants with stroke showed improvements on SF-36 during the nine months intervention which indicated that their health related well-being and activity were approaching that of the general Norwegian population adjusted for age and gender.

- Regular social group activities and meeting with peers are recommended in later phase after stroke.

- Senior centres seem to be an appropriate arena for creating social relationship and social activity among older adults.

- Older adults with stroke may perceive the stroke as a threat to social inclusion, dignity and control of everyday life. At the same time they reconstruct occupational balance by addressing enjoyable occupations in a variety of ways.

Sammendrag

Bakgrunn:
Behandlingsmuligheter i akuttfasen ved hjerneslag har hatt en positiv utvikling de siste årene. Forebyggende tiltak rettet mot hjerneslag har bidratt til redusert dødelighet, og forekomsten av de med milde og moderate hjerneslag har økt. Et paradoks ved denne positive trenden kan være at mindre oppmerksomhet rettes mot rehabilitering, siden mange med hjerneslag ser ut til å være selvstendige i de mest grunnleggende daglige aktiviteter ved utskrivelse fra sykehuset.

Eldre med hjerneslag erfarer ofte angst, depresjon og redusert sosial deltagelse i hverdagslivet flere år etter hjerneslaget. Omtrent halvparten av de med hjerneslag rapporterer udekkede behov innen områdene; mobilitet, fall, inkontinens, fatigue/tretthet og trivsel opp til fem år etter hjerneslaget.

Rehabilitering etter hjerneslag vektlegger særlig individuell intervensjon de første seks månedene. Det er behov for videre forskning innen utvikling og evaluering av rehabilitering i senere fase etter hjerneslaget rettet mot å bedre trivsel, aktivitet og sosiale deltagelse. Det er også manglende kunnskap om hvordan eldresentre kan være en arena for å bidra til å forebygge sosial isolasjon for eldre med hjerneslag.

Mål med studien:
Det overordnede mål for studien var å utvikle, gjennomføre og evaluere et livsstilsprogram ved eldresentre for personer med hjerneslag.
De spesifikke målene var å:
1) utforske eldres erfaringer med å benytte eldresenter (artikkel I).
2) undersøke eldres aktivitetsbehov og deres meningsfulle aktiviteter etter hjerneslag ved bruk av Canadian Occupational Performance Measure (COPM) (artikkel II).
3) beskrive utviklingen av et gruppe basert person-sentrert livsstilsprogram for eldre med hjerneslag (artikkel II).
4) undersøke hvordan eldre med hjerneslag erfarte meningsfulle aktiviteter i hverdagen, analysert i et aktivitetsperspektiv (artikkel III).
5) evaluere effekt av et gruppebasert person-sentrert livsstilsprogram rettet mot trivsel, aktivitet og sosial deltagelse for eldre med hjerneslag (artikkel IV).
6) sammenligne trivsel og sosial deltagelse blant deltagerne i vår studie med den generelle norske populasjon i Norge ved bruk av Short Form Questionnaire -36 (SF-36) (artikkel IV)

Materiale og metode:
Deltagerne i artikkel I var registrerte brukere og frivillige (n=636) som benyttet seg av eldresenteret mer enn to ganger årlig.

Artiklene II, III og IV omfatter undergrupper av totalt 204 pasienter med hjerneslag som ble inkludert fra seks sykehus i to kommuner i Norge i perioden juni 2007 til desember 2009. Deltagende observasjon, halv-strukturerte intervju (COPM) og fokusgruppe intervju var metoder for datainnsamling. En randomisert kontrollert studie ble anvendt for å studere effekt av en ukentlig gruppebasert livsstilsintervensjon som supplement til et fysisk aktivitetsprogram. Begge programmene startet tre måneder etter hjerneslag og foregikk over ni måneder. Kvalitative, kvantitative og fortolkende analyser ble benyttet.

Resultater:
Deltagernes erfaringer med å benytte eldresenter var forskjellige og ble kontinuerlig utviklet, utfordret og forhandlet. Flere brukere erfarte en spenning mellom en 'følelse av trivsel'

knyttet til eldresenterets' aktiviteter og sosiale muligheter og en subtil 'følelse av trussel' ved at det å være på eldresenteret minnet om deres uunngåelige personlige aldring. Denne studien kaster lys over et paradoks flere eldre møter: de er oppmuntret til å opprettholde en ungdommelighet og omfavne en sunn og aktiv aldring samtidig som de blir eldre dag for dag. Seniorsentre gir tilbud om sosiale møtepunkter og ser ut til å ha et potensial som en arena for rehabilitering etter hjerneslag.

Deltagerne med hjerneslag rapporterte stor variasjon i aktivitetsbehov. I alt 132 deltagere rapporterte problemer med aktivitetsutførelse innen områdene: mobilitet, fungere i samfunnet, husarbeid, fysisk krevende fritidsaktiviteter og sosiale aktiviteter. Disse aktivitetsområdene ble arbeidet med som tema i livstilsgruppene gjennomført ved fem eldresentre. I tråd med deltagernes ønsker og valg ble også nye tema utviklet som f.eks.: informasjon om hjerneslag og forebygging av nye hjerneslag, utendørs mobilitet, transport, 'hjernetrim' og hukommelse. Det å involvere deltagerne til å utvikle og bestemme innholdet i intervensjonen bidro til stor variasjon av tema i de ulike gruppene.

Fokusgruppeintervju med åtte av deltagerne skapte innsikt i en tvetydighet hvor hjerneslaget ble oppfattet som en trussel mot sosial inklusjon, verdighet og kontroll. Samtidig opprettholdt de aktivitetsbalanse ved å utføre lystbetonte aktiviteter på nye måter.

I den randomiserte kontrollerte studien ble 204 personer med hjerneslag inkludert, hvorav 99 (49%) ble randomisert og hvor 86 (87%) deltagere (gjennomsnittlig (SD) alder 77.0 (7.1) år) gjennomførte alle evalueringene (39 i intervensjonsgruppen og 47 i kontrollgruppen).

Et gruppebasert person-orientert livsstilsprogram som supplement til et fysisk aktivitetsprogram viste ingen statistisk signifikant effekt på trivsel, aktivitet og sosial deltagelse for eldre med lettere til moderate hjerneslag.

Sammenlignet med det norske normmaterialet av SF-36 justert for kjønn og alder viste deltagerne med hjerneslag redusert helserelatert trivsel og aktivitet ved baseline. Etter 9 måneder forsvant flere av disse forskjellene, noe som indikerer at bedringer kan forekomme i senere fase etter hjerneslag.

Studien viser at det kan være tilstrekkelig med en intervensjon rettet mot å komme ut regelmessig og møte andre i samme situasjon for å bedre trivsel, aktivitet og sosial deltagelse. Denne studien bringer frem utfordringer knyttet til å utvikle, gjennomføre og evaluere en kompleks psykososial intervensjon.

Kliniske implikasjoner

- Et gruppebasert livsstilprogram som supplement til fysisk aktivitetgruppe viste ingen ytterligere statistisk signifikant effekt på trivsel, aktivitet og sosial deltagelse etter hjerneslag

- Alle deltagerne viste bedringer på SF-36, noe som indikerer at de ett år etter hjerneslag nærmer seg en norsk populasjon justert for kjønn og alder.

- Regelmessig tilbud om sosial aktivitet i gruppe med personer i samme situasjon anbefales i senere fase etter hjerneslag.

- Eldresenter ser ut til å være en arena for å skape sosiale relasjoner og sosial aktivitet blant eldre med hjerneslag.

- Eldre med hjerneslag kan oppleve hjerneslaget som en trussel mot sosial inklusjon, verdighet og kontroll i hverdagen. Samtidig viser de kompetanse i å rekonstruere aktivitetsbalanse ved å gjøre aktiviteter de liker på nye måter.

Abbreviations

ADL	Activities of Daily Living
CMOP-E	The Canadian Model of Occupational Performance and Engagement
CONSORT	Consolidated Standards of Reporting Trial
COPM	The Canadian Occupational Performance Measure
HADS	The Hospital Anxiety Depression Scale
ICF	The International Classification of Functioning, Disability and Health
RCT	Randomized Controlled Trial
SF-36	Short Form Questionnaire -36
TIA	Transient Ischaemic Attack
TUG	Timed Up and Go
TMT	Trail Making Test

1. Background

1.1. The ageing population

It is a worldwide phenomenon that the rate of older adults in the population is increasing due to the new demography of declining fertility and low mortality [1]. Ageing processes are modifiable and people are living longer without severe disability [2]. There is evidence for the postponement of limitations and disabilities, despite an increase in chronic diseases and conditions due to early diagnoses, improved treatment and amelioration of diseases. Many factors might have contributed to the reduction in disability such as; the use of assistive technology, public transport, accessibility of buildings, changes in health and social policies, shifting gender roles, educational attainment and income among older adults and improved living [2]. Increasing numbers of older adults, with less disability and fewer functional limitations, can be seen as a success story for public health and socioeconomic development, but it also challenges society to adapt and to enhance health and functional capacity of older people as well as their social participation and security [1]. This finding, together with technological and medical development, will be important for our opportunities as health workers to meet the challenges of ageing populations.

Older adults with stroke who are 65 years and over are particularly addressed in this thesis since the incidence of stroke is strongly age-related and because this age group is often excluded from clinical trials [3].

1.2. Older adults with stroke

Stroke is a leading cause of disability worldwide and even with stable incidence rates, the prevalence is expected to increase due to ageing of the population [4]. Also, stroke mortality is probably increasing more rapidly than stroke incidence in Western countries [5]. Consequently the proportion of stroke survivors is likely to increase. Estimates of lifetime risk of stroke showed, in the Framingham study, that one in six or higher will experience stroke in their lives [6]. Kunst et al. addressed future trends in stroke mortality risk in seven Western countries (Denmark, Finland, mainland France, the Netherlands, Norway, Sweden, and England and Wales) and suggested that despite decline in stroke mortality risk the absolute number of deaths from stroke will probably increase in the shorter and longer term due to the ageing population [7].

There is no exact research regarding incidence and prevalence rates in Norway, but approximately 15 000 individuals are affected by stroke annually and about 55 000 are living with stroke [8]. Sixty-five per cent of stroke cases are ≥75 years old [9].

Stroke is defined as a clinical syndrome with rapidly developing signs of focal or global disturbance of cerebral functions lasting more than 24 hours. Transient Ischaemic Attack (TIA) is defined as symptoms lasting for less than 24 hours. In this study, ischaemic stroke and TIA are considered to be a single entity in line with the European guidelines [10] particularly because there seems to be similar clinical needs for people with mild and short lived stroke as for people with TIA [11]. A cohort study in the United States of 7740 people after stroke demonstrated that there were approximately 80% with mild to moderate stroke; 49, 3% had a mild stroke which indicated that they had no aphasia or unilateral spatial neglect, no major motor problems, were able to manage all activities of daily living, had enough mobility to get in and out of bed, and was able to transfer to the toilet. 32.8% of this sample had a moderate stroke those typically seen for rehabilitation services and 17.9% had severe stroke [12].

Older adults with stroke often experience anxiety, depression, lack of meaningful activities, poor health related quality of life and restrictions in social participation within their daily lives [13-15]. However a systematic literature review showed that the prevalence of depressive symptoms after stroke varied from 5% to 54% and an association was found between early depressive symptoms after 12 months [16]. Also restrictions of participation in activities of daily living (ADL) and social roles after stroke vary and are attributable to ageing as well as to the stroke itself [17]. Age is also identified as a predictor of reduced social participation up to four years after stroke [18]. Almost half of the stroke survivors reported unmet needs including mobility, falls, incontinence, fatigue, and emotional well-being for up to five years after stroke [19].

The adjustment process to improve well-being and social participation after stroke is physically and emotionally demanding, often gradual and prolonged [4;20] and can be understood as a 'life-project' [20]. Different patterns of changes have been identified however despite improvements in daily activities many show dissatisfaction with life as a whole 12 months after stroke [21].

1.3. Interventions after stroke

Optimal organization of multi professional rehabilitation for stroke patients has been extensively documented during the last 10 years [22]. Treatment and rehabilitation in stroke units combined with early supported discharge can reduce death and institutional care and can improve patients' chances of living at home up to five years after a stroke [23].

With the evolution of acute stroke treatment and better prevention of cardioembolic stroke, the case fatality rate has decreased and milder deficits are becoming relatively more prevalent [24;25]. A paradoxical effect of this positive trend may be that less attention is paid to rehabilitation, since many stroke survivors appear to be independent in basic functioning on discharge from hospital [26]. To respond to trend of decline in stroke mortality risk more emphasis on preventive strategies and improved rehabilitation methods to reduce disability and co-morbidity among older adults after stroke is recommended [7]. People living with stroke continue to have modifiable risk factors that could be better managed after discharge from hospital. However there are few community based programmes available that offer the opportunity to address health and social issues associated with long-term recovery from stroke [27]. Current practices of rehabilitation interventions after stroke mainly focus on the first six months and further research is recommended to optimize design, content and delivery of interventions more than six months post stroke [4].

1.3.1. Therapy-based interventions in the community

Therapy based interventions after stroke are usually provided by a qualified physiotherapist, occupational therapist, multidisciplinary staff, or staff under the supervision of qualified therapy staff to improve task oriented behaviour and to reduce disability [28].

A systematic review of randomized controlled trials identified 14 therapy-based intervention studies: four multidisciplinary studies, two studies within physiotherapy and eight within occupational therapy [28]. These studies mainly emphasised personal activities of daily living and mobility and suggested that therapy-based rehabilitation services could be beneficial.

1.3.2. Occupational therapy based interventions

A literature search was conducted in collaboration with a librarian to identify community-based occupational therapy interventions after stroke. Relevant literature was sought, using Ovid Medline, PsycInfo, AMED and Cinahl (15 October 2010). Fifty seven publications were

identified. Four studies were literature overviews [29-32]. Among the other 53 studies, 48 covered occupational therapy, six included multidisciplinary interventions and two studies addressed specific nursing. The identified therapy-based intervention studies were further categorized in line with the International Classification of Functioning, Disability and Health (ICF) [33](Appendix 1). This categorization enlightened that the main focus on these interventions were in the acute phase and addressed personal self-care, dressing and outdoor mobility. Related to ICF, the interventions emphasised impairment and body function level. Improvements to undertake personal activities of daily living were demonstrated; however, the exact nature and content of therapy-based interventions were not addressed in these studies. Wolf et al. suggested that the focus on rehabilitation interventions related to personal care have therefore ignored the importance of participation within the complex social context of everyday life [12].

Despite good functional recovery after stroke there is a further need to understand barriers to occupational engagement when the aim is to enhance social participation, occupation and well-being [34]. There seem to be a paucity of interventions which go beyond personal care which can be promising for those with mild to moderate stroke. Therefore in the following, intervention studies addressing psychosocial factors, participation and self-management will be presented.

1.3.3. Psychosocial interventions

Interventions designed to modify social networks, enhance social support, promote social integration and improve health and functional outcomes can be described as psychosocial [35]. Glass et al examined whether a psychosocial intervention influenced social support and self-efficacy in older stroke patients [36]. The intervention was provided in the home of the stroke survivor and involved the person's entire network (such as primary caregiver, friends, family, neighbours, and associates, plus professional care providers). Although those who participated in the psychosocial intervention showed greater improvements than the control group, the differences were not statistically significant.

Concerning social participation two studies were identified which addressed this in community-based occupational therapy interventions three months after stroke [26;37]. The first study showed that a model of social support delivered three to six months after stroke moderated the effect of functional limitations and community participation [37]. The authors suggested that occupational therapists need to expand their practices to include promotion of

social support and community participation after stroke. The second study tested the effect of a community and occupation based intervention six months after discharge from a rehabilitation unit. This intervention showed a potential to enhance participation in valued activities [26]. There appears to be a need for evaluating the effectiveness of interventions addressing psychosocial factors including depression, social support and social activity after stroke [35].

1.3.4. Lifestyle and self-management oriented interventions

The therapy-based and the psychosocial interventions after stroke identified in the literature search, appeared to emphasise interventions offered at individual level. However there are also psychosocial programmes offered as group interventions which might be promising for older adults after stroke. A systematic review suggested that educational and social activity group interventions that target specific groups of people can alleviate social isolation and loneliness among older people [38]. Self-management programmes are often provided in groups and may be useful for people with a long-term condition including stroke where adjustments such as learning new behaviours and/or modifying lifestyle becomes a necessity [27]. Such programmes involve the patient's central role in managing their illness. Self management programmes emphasise skills mastery, reinterpretation of symptoms, modelling of self-management behaviours, problem-solving strategies and social persuasion through group support to enhance a sense of self-efficacy and guidance for individual self-management efforts [27;39].

A community based lifestyle oriented group intervention for older adults was developed in the USA called the Lifestyle Redesign ® programme [40-42]. The aim was to promote physical health, daily functioning and psychosocial well-being. A randomized controlled trial (The Well Elderly study 1) of 361 older adults showed statistically significant improvements in the intervention group on health, function and quality of life domains [43]. These improvements were maintained after six months [44]. The intervention also showed cost-effectiveness by reduced expenditure for medications [45]. This programme had detailed descriptions about how to develop and implement an intervention. Modifications adapted to local cultural contexts published in the UK [46], Denmark [47], Sweden [48] and Norway [49] also covered detailed descriptions of the development and implementation of a lifestyle oriented intervention. In Norway I was involved in the modifications of the programme to Norwegian conditions [49] which also inspired implementation of this programme for older adults with stroke. To our

knowledge this programme had not been evaluated for older adults after stroke. The programme was provided as group intervention and individual follow ups. Methods applied were addressing self-reflection, self-management, person-centredness, participation and occupation which could be appropriate approaches for older adults after stroke. Inspired by the promising results in USA and from the pilot studies in UK, Denmark, Sweden and Norway we decided to develop, implement and evaluate a lifestyle and group oriented programme for older adults after stroke to enhance occupation, participation and well-being.

1.4. Framework for understanding the relationship between occupation, participation and well-being

A theoretical basis is suggested when developing effective interventions offering social activity within a group approach [50;51]. In this study occupational science [52] and the Canadian Model of Occupational Performance [53] were applied as theoretical framework in the process of developing and implementing the person-centred lifestyle intervention. These perspectives were applied to understand the relationships between the participants' occupation, participation and well-being in their daily lives after stroke.

1.4.1. Occupational science

Occupational science is a discipline addressing and studying the form, function and meaning of human occupation [42] including the need for, and capacity to, engage in and orchestrate daily occupations in the environment over the lifespan [54;55]. Occupation is understood as a fundamental basic human need and refers to everyday activities or tasks people do to occupy themselves such as looking after themselves, enjoying life and contributing to social life [53]. The occupations people choose to do influence their lifestyles, their social relationships, their health, well-being, and participation in society [52].This understanding addresses the relationship between health and occupation and underpins the importance of human participation in occupations of daily life. Although occupational science is viewed as a basic science that contributes to the understanding of occupational therapy, the field is also developing theories and research that are multidisciplinary and related to other fields [55].

1.4.2. The Canadian Model of Occupational Performance

The field of occupational science and the profession of occupational therapy share a common interest in understanding human occupation; also different models for understanding

occupation and guide clinical work have been developed. The Canadian Model of Occupational Performance and Engagement (CMOP-E) was chosen as a theoretical model to understand the dynamic relationship between the person, the environment and the occupation that resulted in occupational performance and engagement in everyday life [53]. In the CMOP-E, everything people do to occupy themselves are classified within; self-care (including looking after self), leisure (enjoying life), and productivity (contributing to the social and economic fabric of their communities). The CMOP-E was also applied to guide the researchers and occupational therapists in using a person-centred occupation based approach which means to put enablement as the core of a person-centred practice. This focus on the individual's participation is a central feature of enablement and is shaped by his/her interests, perspectives, needs, expectations, desires, motivations, social conditions, resources, dreams, hopes and visions of possibility [53]. The Canadian Occupational Performance Measure (COPM) is derived from the CMOP-E and was chosen as a tool in the needs assessments and as a secondary outcome measure to evaluate change over time in our study.

1.4.3. Occupational justice in a Western consumer culture

The concept of occupational justice has been developed from social justice and shares common beliefs in societies by a set of ethical, moral and civic principles related to fairness, empowerment, equal access to resources and sharing of rights and responsibilities [56]. Social justice addresses the ways in which humans treat and relate to each other and to the distribution of material wealth and the opportunities which follow that wealth [56]. Occupational justice is grounded in the belief that humans are occupational beings and participate in occupations as autonomous agents [57]. What people want to do, need to do and can do is emphasised and implies that different societies and cultures value different occupational capacities and meanings [56]. The occupations people choose to do influence their lifestyles, their social relationships, their health, well-being, and participation in society [52]. This understanding addresses the relationship between health and occupation and underpins the importance of human participation in occupations of daily life. The right to participate in occupations and the vision of an occupationally just world emerged as a concept of 'occupational justice' late in the 1990s, addressing social inclusion of persons, individually and collectively in everyday occupations of societies [56;58]. Occupations are shaped by the cultural values and norms of the societies [59].

Cultural values are described as one of the occupational determinants and regulate what

people do and how they are rewarded [57]. This means that occupational justice and injustice are embedded in the culture and can be constructed in different subtle ways within different cultural contexts. Understanding the role of culture in contemporary society is crucial to an understanding of the position of older adults [60]. The various cultures of ageing each have their own representation of old age [61]. The standpoint of this thesis is that culture is a dynamic system in which human beings weave self-made meanings, and that these are created, negotiated, contested and changed through interactions with others and the environment. The culture is complex; it has been described as 'the air that we breath'[62;63], and it is continuously in flux and contradictory, which gives rise to different meanings. Many have seen contemporary Western culture as first and foremost one that creates a general expectation of staying young [64], in contradiction to the unavoidable fact that we all age day by day. If the consumer culture has been created mainly by the media, arguably it is reinforced by health-care and social policies that promote healthy lifestyles and encourage 'active ageing', physical activity and good nutrition. The context of this study is coloured by the Western consumer culture.

From a Western perspective occupational justice has been described as a justice for difference: a justice to recognize occupational rights regardless of age, ability, gender, social class or other differences [65]. In an occupational just world, access to participate in occupations of personal meaning and societal value is seen as a right [53]. Townsend and Wilcock suggested four occupational rights: the right to experience occupation as meaningful, the right to develop through participation, the right to autonomy through choice of occupations, and the right to benefit from fair privileges for diverse participation in occupations [58]. Occupational injustice emerges when participation in occupations is barred, confined, marginalized, exploited, excluded or otherwise restricted [58]. Four overlapping outcomes of social exclusion are proposed as a part of the ongoing dialogue in the concept of occupational justice.

(1) Occupational alienation is referred to as social exclusion by restricting a population from experiencing meaningful and enriching occupations [66].

(2) Occupational imbalance concerns the allocation of time use for particular purposes so that some people have too little to do (under occupied) while others have too much to do (over occupied) in their daily lives. Imbalance is also recognized as lack of congruence across one's occupations or between occupations and cultural core values [67].

(3) Occupational deprivation is defined as a preclusion from engagement in occupations of necessity and/or meaning due to factors which stand outside of the control of the individual

which can arise from social and cultural practices and can create stigmatization[59].
(4) Occupational marginalization occurs when people are not afforded the opportunity to participate in occupations and operates often in subtle ways through expectations of how, when, where and which person should participate in occupations [57].

These outcomes are interwoven and related to the rights to perceive meaningful and purposeful occupations, social inclusion, participation, choice and balance in daily occupations [57;65]. An occupational justice lens may be used to meet the vision of an occupational just world by enabling the empowerment and social inclusion of people who experience social exclusion [65]. The relationship between occupation, participation and well-being in a Western cultural context were cornerstones in the development, implementation and evaluation of this person-centred lifestyle programme.

2. Aims of the study

The *overall aim* was to develop, implement and evaluate a lifestyle intervention conducted at senior centres for older adults after stroke.

The specific aims were to:

1) investigate older adults' inter-personal experiences of attending a senior centre (paper I).
2) explore older adults' occupational needs and issues of importance after stroke by application of the Canadian Occupational Performance Measure (COPM) (paper II).
3) describe the development of a group based person-centred lifestyle intervention for older adults after stroke (paper II).
4) explore how older adults experienced occupations in their lives following a stroke, analyzed in an occupational justice framework (paper III).
5) evaluate the effectiveness of a group based person-centred lifestyle intervention on well-being, occupation and social participation for older adults after stroke (paper IV).
6) compare well-being and social participation among the sample in our study with the general Norwegian population by using the Short Form Questionnaire -36 (SF-36) (paper IV).

3. Participants and methods

Two populations were addressed in this study; i) older adults attending a senior centre and ii) older adults with stroke. Overview of studies 1-IV related to participants and methods:

	Participants	Methods	Analysis
Paper I	Older adults attending a senior centre more than twice a year (n=636)	Participant observation	Interpretive approach in a Western cultural context
Paper II	Older adults with mild to moderate stroke recruited from six hospitals (n=132, which is a sub-group of total n=204)	1) Individual needs evaluations by COPM 2) Utilization of COPM results in groups to develop intervention content	1) Occupational performance problems were categorized and summarized. 2) Findings from the individual COPM and group themes were categorized
Paper III	Older adults with mild to moderate stroke (n=8, which is a sub-group of total n=204)	Focus group interviews	Interpretive approach in a Western cultural context
Paper IV	Older adults with mild to moderate stroke recruited from six hospitals (n=204) whereby 99 were randomized and 86 participants completed all assessments (39 in the intervention group and 47 in the control group)	Randomized controlled parallel trial with two arms: 1) Active arm: a lifestyle group in combination with physical activity 2) Control arm: physical activity	Analysis of covariance (ANCOVA) was used for differences in the primary and secondary outcomes. The paired-samples *t* test for within-group comparison.

3.1. Participants

3.1.1. Older adults attending a senior centre (Paper I)

The participants were drawn from the 2,339 registered older adults aged 60 years and over in a community in Oslo. In 2004 there were 636 registered older adults attending a local senior centre in this community more than twice a year. Some visited the centre as a user and others contributed as volunteers. Women were the main users and 19 % were men. The average age was 77 years, and 44 % were aged 80 or more years. Each day 20 to 70 seniors visited the centre. Some attended for a specific reason, such as to visit the hairdresser, for the French course, to have a meal or to meet people. Others visited the centre regularly and talked with people they met every day. The volunteers undertook many tasks at the centre, for example managing the café, doing office work, welcoming new users, organizing the bridge or computer groups [68]. Senior centres as the context for the intervention is described further in the methods section.

3.1.2. Older adults with stroke (Paper II, III, IV)

Studies II, III and IV were conducted using different subsamples of the 204 included stroke patients from six hospitals (Ullevaal, Aker, Diakonhjemmet, Lovisenberg, A-hus and Bærum) in two municipalities in Norway. They were consecutively included from June 2007 until December 2009. A contact person (nurse or occupational therapist) was appointed at each hospital. She contacted the researcher (AL) when an eligible stroke patient agreed to participate in the research project. The project leader or the project assistant (MM) met the patient at the hospital, close to discharge, in order to obtain the written consent, confirm the inclusion criteria, and give further information about the project as required. The *inclusion criteria* were the ability to give written consent at time of discharge; clinical diagnosis of stroke or TIA determined by a physician; a Mini Mental Status Examination (MMSE) score above 23 (max 30) [69] and a Barthel ADL Index score $\geq$14 (max 20) [70;71]. *The exclusion criterion* was severe communication problems, evaluated as a score below 33 (max 52) in the Ullevaal Aphasia Screening Test [72].

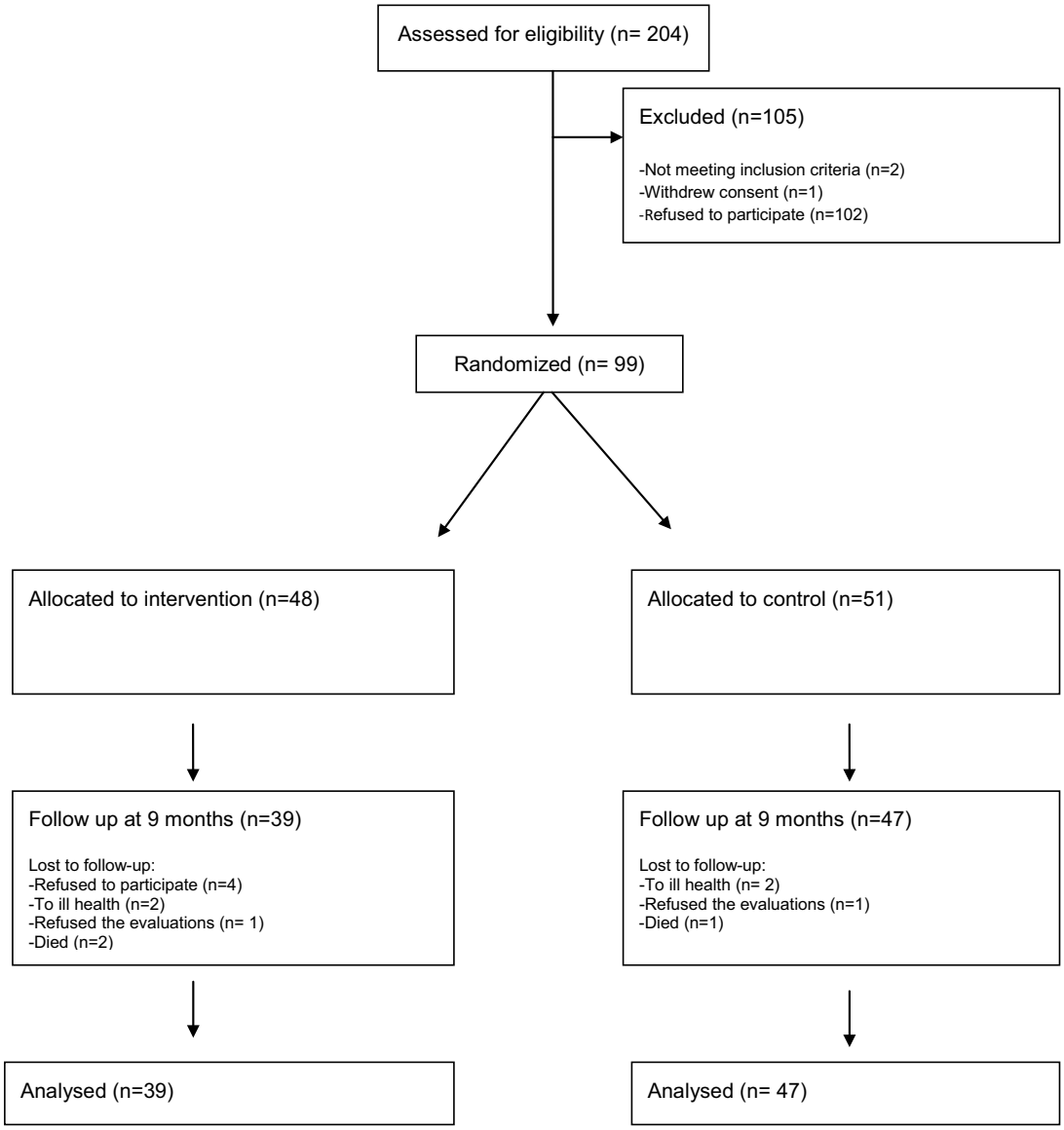
Paper II addresses the 132 participants who prioritized occupational problems in the semi-structured interviews by using the Canadian Occupational Performance Measure. The results from these interviews were utilized in the lifestyle groups. The median age (interquartile range) at inclusion was 79 (73-84), 55% female and 60% living alone.

Paper III describes the first eight participants (five women and three men) randomized to

lifestyle groups. Their age range was 69-88 years.

Paper IV addresses 204 participants invited to participate in the trial. Due to time and funding constraints, we finalized when 99 (49%) accepted participation in the programmes. At nine months, 86 (87%) completed the assessments (mean age (SD) 77.0 (7.1) years). Figure 1 shows the flow chart of the participants.

Figure 1. Flow chart of the participants in the RCT (paper IV)



3.2. Methods

Detailed description of intervention components, structure, process, theoretical basis and outcomes are needed to compare and replicate successful complex interventions in clinical practice. These are often lacking in the reporting of complex rehabilitation interventions [73;74]. The Medical Research Council in the United Kingdom developed a framework for developing and evaluating complex interventions [75] which were updated [73] and the new guidance provided a more flexible model [51]. We were inspired by this framework when designing, implementing and evaluating this study. This was applied as an ongoing flexible process and did not follow a linear sequence (Figure 2). Qualitative and quantitative approaches can be seen as complementary in medical research [76] and have been applied in this project to understand the complex phenomena of the development, implementation and evaluation of a lifestyle intervention for older adults after stroke. Complex interventions include several components [75]. In our study this meant a community based group intervention programme including psychosocial components related to self-management, learning new behaviours and adjusting to everyday life after stroke. Further presentation will emphasise the development, evaluation and implementation of the study and feasibility/piloting will be integrated. Figure 3 presents an overview of our application in this study.

Figure 2 Key elements of the development and evaluation process [51]

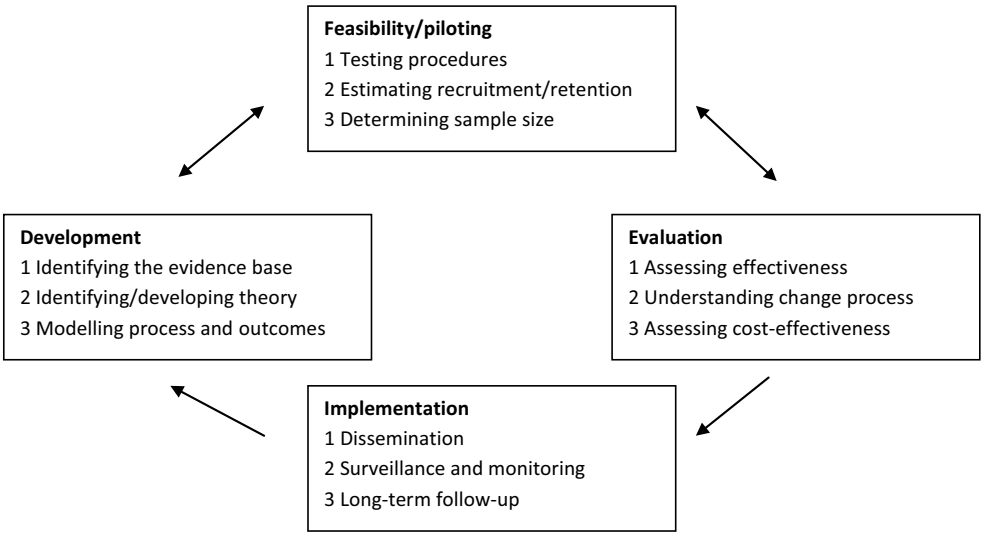
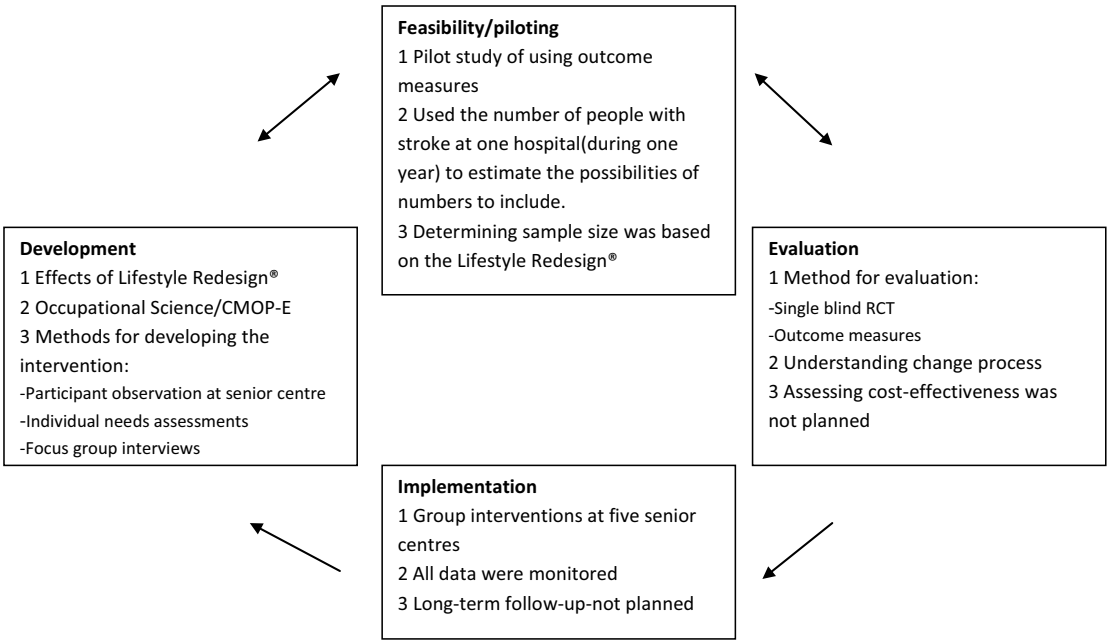


Figure 3 Key elements related to the development and evaluation process in this study



3.2.1. Development

The development of the life style intervention programme was inspired by the original Lifestyle Redesign ® (LR) programme [40-42] as previously described (1.3.4.). Methods applied to develop the intervention were participant observation at a senior centre (paper I), individual needs assessments (paper II*)* and focus group interviews (paper III).

Participant observation at a senior centre (paper I)

Participant observation was used to gather data about the older adults' communal activities and interactions at a senior centre. To approach an understanding of the meanings that the users of the centre had of its own activities [77], I attended the centre for about 100 hours spread over 17 days during three months. Field notes were written at the centre and carefully recorded at the end of each day. I worked as a volunteer, which enabled interactions and collaboration with the seniors [78]. Instead of just observing, I participated in the activities, such as serving meals, activity groups, the management of the cafe´ and office work. It should be recognised, however, that I was not of the same age or in the same social situation as the senior users. I had a dual perspective that fluctuated between distance from and closeness to

the senior users, comparable to an apprentice in the workplace [79]. The centre's activities were unfamiliar to me, which created many opportunities to ask questions and learn from the users, and encouraged the sharing of experiences through 'doing' and 'saying'. I interpreted the shared experiences by applying my occupation-focused approach that was sensitised to the ways in which the seniors both raised control over their environment and used inter-personal interactions to improve their well-being [80].

Selection of senior centres for the intervention

To select senior centres for the interventions I visited several senior centres and had a meeting with the managers and invited them for collaboration. Five centres were chosen in line with those centre managers who agreed to participate in the project. To participate in the project meant to offer a room at the centre for lifestyle group sessions, a room and a volunteer to conduct the physical activity group. A local occupational therapist was invited to conduct the life style group sessions in collaboration with me.

Individual needs evaluations (paper II)

The process of developing the content of the lifestyle programme began with the individual needs evaluations of the group participants, conducted as semi-structured qualitative interviews [81] in the participants' homes approximately three months after stroke. The Canadian Occupational Performance Measure (COPM) was used for the individual needs evaluations to describe the qualitative and the quantitative aspects of occupational performance [82;83] . The COPM also served as a tool to facilitate the participants' awareness of their occupational challenges in their lives after stroke. The COPM is conceptually grounded in the CMOP-E, and is widely used as a tool to aid patients and clinicians in defining goals, planning interventions and evaluating changes in occupational performance over time. It is well documented for use with people who have had a stroke [84;85]. The Norwegian version has been tested for psychometric properties and found feasible both within clinical practice and research [83;86;87]. Each COPM needs evaluation was initiated by the open question: *'Could you please tell me what you do during an ordinary day?*' The participant was then asked: *'Are there any activities with which you have problems?*' In the next step the participant prioritized up to five of his/her occupational performance problems within nine areas: personal care, functional mobility, community management, (self-care), paid/unpaid work, household management, play/school (productivity), quiet recreation, active recreation, and socialization (leisure). Each activity was then rated for importance on a scale from 1 to 10, (1

= ‘not important at all’; 10 = ‘extremely important’). The participants also rated each activity for performance and satisfaction on a scale of 1 to 10, with 10 representing optimal performance or satisfaction. At the first two group sessions the group leader (AL) utilized the findings from the individual COPM interviews by inviting the participants to share themes they found important. Questions from the individual COPM interviews were repeated followed by focus group discussions, which enabled the tailoring of the intervention content.

Focus groups (paper III)

Focus group interviews were used to explore important occupations of daily life experienced by the participants and analysed qualitatively. This means that the ’researcher’s positioning’ was of great importance in the process of analyzing the material. Accordingly this study should be seen as a situated activity which located me in the ‘world’ attempting to make sense of what the participants addressed [77]. This situated activity was influenced by being in a double role as a researcher and a focus group leader. I participated closely in the activity within the groups whilst simultaneously maintaining the research focus. There were continuous ongoing dialogues between me and the participants which opened up interpretative and communicative processes. This was a task of both acting upon and reflecting in action [88]. I was striving to understand how the group participants talked about their lives which required her talking and acting in an open-minded way. At the same time I brought in questions to explore the participants’ experiences of occupations of importance within their social and cultural praxis and facilitated the interaction between participants by listening and asking questions enabling them to reflect on and exchange experiences they found important in their lives [89]. All writings were interpretations of interpretations [62]. Through many steps in this process of interpretations, occupational justice finally emerged as a useful analytical frame in line with how the participants expressed their occupations and participation after stroke.

A second group leader was present at the group sessions as a participant observer, and contributed to ensure fresh exchange of reflections after the meetings related to the process that had occurred. Probing questions were asked to capture information related to occupations of importance and challenges in the participants’ daily lives after stroke. Questions applied were: What do you do during an ordinary day? Are there any activities with which you have problems? Are there any occupations you miss being able to do? Which occupations do you

find important to do in your daily lives? In the forthcoming group sessions this contributed as a background for further development of the intervention content.

3.2.2. Evaluation

Randomized controlled trial (paper IV)

A single blind randomized controlled parallel group trial was applied in the evaluation of the effectiveness of the intervention. Randomized controlled trials are accepted as the most reliable method for conducting clinical research evaluating effectiveness by comparing groups and assigning each patient randomly to either the new or standard care to obtain an unbiased evaluation [75;90]. This trial had two arms: lifestyle group participation in combination with physical activity in the active arm, and physical activity only in the control arm. The trial was checked by independent data monitoring and reported in accordance with the CONSORT guidelines [91].

Outcome measures

Evaluations were conducted at baseline, by one of the two assessors. The research assistant performed all the evaluations after six and nine months. All evaluations were conducted in the participants' homes.

A pilot study was conducted to evaluate the feasibility of the outcome measures chosen. The outcome measures were conducted with four patients. These experiences were discussed with the patients. The outcome measures were found to not require too much effort from the patient and lasted for approximately one and half hours to two hours. However the design of SF-36 was adapted by some lay out changes adapted for visual problems. Experiences from this pilot enabled both the assessors to perform the baseline assessments in similar ways.

Primary outcome measure: Medical Outcomes Study 36-item Short Form Questionnaire (SF-36) was applied which is an internationally recognized measure of perceived health and well-being consisting of eight subscales; *mental health, vitality, bodily pain, general health, social functioning, physical functioning, role physical and role emotional.* The subscales are scored and transformed to a 0-100 (highest level of functioning) scale [92-95] .

Secondary outcomes measures: the Canadian Occupational Performance Measure (COPM) which is a reliable and valid instrument used to measure change in self-reported occupational performance and satisfaction of up to five occupational issues rated on a scale on 1 to 10, ten representing optimal performance or satisfaction[86;96]; the Hospital Anxiety and Depression Scale (HADS) consisting of two subscales (anxiety and depression) ranging from 1 to 21

(highest level of anxiety or depression) [97]; the Timed Up and Go (TUG) to assess mobility [98]; and the Trail making test (TMT) A and B for aspects of cognitive function, [99]. The outcome measures related to the aims of the intervention presented in Table 1.

Table 1 Outcome measures used at baseline, after six and nine months

	SF-36 **Self rating**	**HADS** **Self rating**	**COPM** **Interview**	**TUG** **Observation**	**Trail making test A and B** **Observation**
Well-being	x	x	x		
Activity	x		x	x	x
Participation	x		x		

3.2.3. Implementation

Both the lifestyle course and the physical activity programme were offered as group sessions over a nine months' period. The programmes were provided three months post-stroke at five different senior centres.

Senior centres

Findings from paper I contributed to increased knowledge about senior centres as a context of the intervention. Senior centres are open meeting places outside the health-and social services. The centres are mainly run by private organizations and volunteers. The senior centre's mission statement focuses on the promotion of ' thriving, security, social contact and networks, stimulating experiences in daily life, good food, inclusive atmosphere, information and guidance regarding personal economy, nutrition, health, activity and assistance in practical activities'. 'Thriving' is emphasised and in this context associated with 'good health' and 'subjective well-being', consistent with terms used in social gerontology [68;100]. This study contributed to the awareness that older adults attending senior centre can experience the senior centres as a place which can reveal an ambiguity of 'thriving' and 'threat'. A 'sense of thriving' was related to the centre's activity and social opportunities provided, while a subtler 'sense of threat' was revealed through their perceptions of the centre as a place for older and frailer users from whom they wished to distance themselves. This could probably influence

the participation rate. Therefore during the recruitment process we used this opportunity to ask and inform the participants about the local senior centres. The senior centres were found to be feasible due to these centres being in the participants' local environment and also that the senior centre's mission statement was compatible with the objectives of the lifestyle intervention. The choice of using senior centres contributed to providing both interventions (lifestyle groups and physical activity group) in a similar context. Another justification of choosing the senior centres as a context was that high age and specific health problems led to increased use of senior centres and the association with age could not be explained through socio-demographic, psychosocial or health variables [101]. Evaluations, such as randomized controlled trials, need to be conducted to include both users and non-users of senior centres [102].

Delivery of the programmes

Each participant in the intervention group was offered 36 sessions of the lifestyle course and 36 sessions of physical activity. The controls had 36 sessions of physical activity. All the participants received a phone call prior to each session. Transportation was provided for those who needed it. In the implementation period (10.3.2008 to 11.11.2010) 374 physical activities group sessions and 374 lifestyle group sessions were conducted. I coordinated these groups in collaboration with the group leaders at each senior centre and conducted or participated in 286 group sessions.

The lifestyle intervention

Each session was conducted once a week for two hours by a local occupational therapist in collaboration with me. The intervention content was influenced by initial individual needs evaluations. New participants joined groups continuously. The group leaders utilized principles of life management, healthy living and habit change [41] inspired by cognitive-behavioural therapy to involve the participants in education, problem-solving and self-reflections of their daily lives [103;104]. To enhance person-centredness the group leaders continuously enabled the participants to choose, organize and perform those occupations they found meaningful by using peer exchange, self reflections, direct experience by performing occupations and didactic presentation[40]. The latter was information presented to the group by the occupational therapist, other health professionals or one of the group participants. Thus, the intervention content was developed continuously through interactions between the participants and the group leaders. This approach increased the variety of themes and ensured

that the content was in line with what the participants perceived as important in their lives. Some examples of the intervention content addressed in the groups were; outdoor mobility and transportation, social networking, physical activities, enjoyable activities, 'brain use' and memory, falls prevention, travelling abroad, life stories, older people in our society, stroke and prevention of further strokes. These themes were addressed through discussions, lectures, physical activity, outings by foot/train/bus to the local area/café/museums, brainstorming and completing individual forms (for example, assessment of own social network). Each meeting was closed with an oral evaluation from the participants. The group leaders made a written evaluation after each session.

The physical activity (for both the intervention and control group)

The physical activity was chosen as 'usual care' because senior centres usually provide this service. The physical activity groups were led by a volunteer at the senior centre and offered once a week from 30 minutes up to one hour. The volunteers were pensioners with special interest in physical activity. The physical activity programmes varied between groups due to variations related to the ordinary services at each senior centre. The exercises mainly included sitting, standing, walking, balance and different mobility activities indoors. The participants were encouraged to work within their safety limitations to prevent injuries and pain.

Training and monitoring of group leaders

The occupational therapists who led the lifestyle courses received a two days seminar with an experienced psychiatrist focusing on how to involve the group participants in education, problem-solving and self-reflections[41]. During the seminar and the group leader meetings (once a month), principles of life management, healthy living and habit change inspired by cognitive-behavioural therapy were discussed[103;104]. This was to ensure that each group intervention was delivered using the same approach.

The volunteers in charge of the physical activity groups were not offered any specific training. Each volunteer had the possibility to design the physical activities in the way they preferred. All the volunteers were invited for a meeting before they started in order to share and discuss appropriate physical activities. They were also invited to a meeting after the intervention was closed to evaluate their groups.

3.3. Analysis

According to the use of qualitative, interpretative and quantitative approaches, a variety of analyses have been used.

3.3.1. Qualitative and interpretive approaches

Participant observation (paper I)

The process of analysis began while developing the research questions and continued as data were gathered [77;79;105]. The field notes were categorised as 'observation notes', 'theory notes' and 'methodology notes'[105].The concerted search for understanding and system in the data involved repeated selections from the three categories of notes and iterative comparisons and changes of perspective. I sought to differentiate the way the material was created from my own experiences and interpretations. Interpretations were closely discussed within the research group. The analysis identified various themes in the seniors' expressions about personal ageing and growing old. In deciding the labels for the themes, terms close to the seniors' vocabulary were preferred. 'Thriving' strategies were emphasised and described as such by the users. We defined the 'thriving' strategies as those that referred to, or engaged with, 'a sense of community', 'the rhythm of daily life' and 'feeling useful '. The notion of 'thriving' in these senses is close to subjective well-being [106;107]. On the other hand it was found that 'threat' strategies were actualised and described in subtle ways. We found that the informants who distanced themselves from the centre and from other attenders connected these thoughts with striving to 'stay young'. We showed how distancing strategies were used both in the users' conceptualisations of the senior centre and in their relations and interactions with others.

Needs assessments (paper II)

The total number of prioritized occupational performance problems from the COPM needs evaluations and the number of participants prioritizing occupational performance problems within each of the nine COPM categories were summarized [82]. The median and the interquartile range of the individuals' ratings of importance, performance and satisfaction (on a scale from 1 to 10) were calculated. The occupational categories in CMOP-E and COPM were applied in the analysis and also the categorization of the content for the four lifestyle groups. After each group meeting the group leader wrote an evaluation describing the aims of

the meeting, the themes and methods applied. These written evaluations were categorized and summarized into main themes, domains of concern, methods and performed occupations.

Focus groups (paper III)

The material in this study consisted of five focus groups lasting approximately one hour. They were audio taped and transcribed verbatim. The process of analysis was inspired by the theoretical framework by Denzin and Lincoln [77] further done in stages inspired by Giorgi [76;108]. The transcribed written material was initially read several times to gain a general impression of how the participants presented themselves in the present and in the past. Further, the interpretation process involved discrimination of meaning units with focus on occupation as a phenomenon in an occupational justice framework. These categories were then condensed and abstracted to meanings within each of the systems of categories. Finally, the contents of the categories were generalized to descriptions and concepts related to the various themes in the participants' expressions about their lives after stroke and different ways of making meanings and changes in the occupations they found important. The analysis identified various themes in the participants' expressions about living with stroke.

3.3.2 Statistical approaches

Descriptive analysis (paper IV)

Continuous variables were analysed by independent samples t-test and categorical variables by chi-square test. Dichotomisations were applied on measures for inclusion. However the primary and secondary outcome measures were regarded as continuous variables.

Power calculation

An 80% power and a 5% significance level required at least 128 participants in order to detect a difference of 5 points (SD10) between the groups. A somewhat higher standard deviation was estimated for this sample compared to that found in the Lifestyle Redesign® programme trial for older people without stroke [43]. We expected 5-10 % missing data and planned to include 140 (70 in each group). To ensure enough patients, 204 were invited to participate.

Comparing groups

Analysis of covariance (ANCOVA) was used for differences in the primary and secondary outcomes adjusted for baseline differences [109]. The paired-samples *t* test was used for within group comparisons between baseline and 9 months. The reference data from the general

Norwegian population (n=2323) of the Short Form Questionnaire (SF-36) [92] was adjusted for age and gender to derive expected mean values, as recommended by Hjermstad et al. [110]. The PASW 18 was used for statistical analyses.

3.4. Ethical considerations

The participants provided signed informed consent to participate following a written and oral explanation of the study. Ethical approval for the study was obtained from the Regional Committee for Medical Research Ethics in the Eastern Health Region, Norway (approval number 194-07084a1.2007.269) and the Privacy Protection Representative at Ullevaal University Hospital (number 838). The study was also registered in Clinical Trials.gov Identifier: NCT00495248.

Participation in the different parts of this study was voluntary and the participants could cease participating at any time without further explanation. The assessments took place in the participants' homes, which could be experienced as an intrusion on their privacy. However the assessors had extensive experiences in rehabilitation after strokes (including home visits) which were valuable in the social interactions in the participants' homes. The assessments did not contain any harmful procedures and lasted for approximately one to two hours. If the participants felt tiredness during the assessments they were invited to fill in some of the questionnaire forms afterwards and return them to the researcher as ordinary mail. Regarding the invitation for participating in group sessions we emphasised that the programme would probably not fit all. The participants were encouraged to find out the appropriateness themselves by attending a couple of sessions. During the nine months intervention the group leaders and the participants established a good relationship. Most participants expressed their positive experiences of participation in both the lifestyle groups and the physical activity groups. A few times some participants expressed major problems related to their everyday life. These situations were handled by supporting the participants to come in contact with appropriate health care professionals.

4. Abstract of the papers - main results

Paper I

Title: 'I am not that old': inter-personal experiences of thriving and threats at a senior centre.

Objective: To illustrate what it means to older people to be 'old' and 'not old' by investigating older adults' inter-personal experiences of attending a senior centre.

Methods: Participant observation was conducted of the interactions between users of a senior centre.

Results: The users held two sets of attitudes that led to quite different activities and actions at the centre. On the one hand, they saw the centre as helping them 'thrive ', which was associated with involvement in the community and participation in the structured daily activities to promote the senses of belonging and being useful. On the other hand, some perceived the centre and particularly the other users as 'threats' – as reminding them that they were getting old and increasingly vulnerable to sickness and disability. To some, the centre was for old people with disabilities and they used subtle strategies to distance themselves from this group. Some users' attitudes and behaviour were in tension: they wished to participate in the valued activities but also to distance themselves from frailer users, while not denying their own ageing. The distancing strategies and behaviour amounted to age discrimination in interpersonal relations and interactions at the centre. This behaviour accepts rather than challenges the cultural value of youthfulness and the negative representation of old age.

Conclusions: The users were often influenced by the Western consumer culture's high value of active ageing, youth, fitness and beauty. The study has raised understanding of the paradoxical situation that many older people face: they are encouraged to remain youthful and to embrace healthy and active ageing while, at the same time, they are becoming older day by day. The senses of community, belonging and social well-being were generated by the centre and valued, but attendance also brought them face-to-face with who they are, what they want to be, and how a person is perceived by others. This experience was found both stabilising and destabilising but was always negotiable. The users articulated who they did not want to be in relation to others; and these expressions revealed various ways of creating distance from one's own ageing. Ageism and occupational injustice were both maintained and contested by the users in various paradoxical ways. The centre's reminders that life is not for ever raised the sense of vulnerability and the existential anxiety of growing old.

Paper II

Title: Development of a person-centred lifestyle intervention for older adults following a stroke or transient ischaemic attack.

Objective: To describe the process of developing a person-centred lifestyle intervention for older adults with stroke.

Methods: The Canadian Occupational Performance Measure was used to develop the content of the intervention. Lifestyle groups were implemented at senior centres once a week for nine months. Content analysis was used to analyse the intervention content.

Results: A total of 132 participants (median age 79 years, 55% women, 52% lived alone) were recruited from hospitals. The participants prioritized 392 occupational problems, mainly related to active recreation, household and community management, mobility, and socialization. The occupational issues were addressed in the group interventions. New themes also emerged in line with the participants' choices through group discussions, such as information on stroke and prevention of new strokes, outdoor mobility and transportation, "brain use" and memory.

Conclusions: The study demonstrated the development of intervention following stroke, addressing its process, structure, and components. Whether the person-centred process increases the potential for enhancing participants' social participation and well-being should be evaluated in future studies.

Paper III

Title: 'Occupational threats' and reconstructions of occupational balance following stroke

Objective: To explore how older adults with stroke experienced their meaningful occupations in everyday life.

Methods: Five women and three men (aged 69 88 years old) participated in focus group discussions. The analyses draw on an occupational justice framework interpreted within a Western culture. Systematic text condensation was applied.

Results: The participants' experiences revealed how active and productive they were before the stroke. This was expressed through their current 'feelings' and 'doings'. The 'stroke' was perceived as an 'occupational threat' relating to feelings of being powerless, dependent, tired and useless. The participants seemed to produce feelings of social exclusion which actualized occupational alienation, deprivation marginalization and imbalance. However at the same time the participants reconstructed occupational balance particularly by addressing enjoyable occupation.

Conclusions: The participants' experiences provided insight into the ambiguity and heterogeneity of how they felt occupational threats after stroke and at the same time were triggered to reconstruct occupational balance. In practice and further research this ambiguity should be considered when developing interventions for older adults after stroke to enhance social participation and undertaking meaningful occupations.

Paper IV

Title: A lifestyle intervention as supplement to a physical activity programme in rehabilitation after stroke: a randomized controlled trial.

Objective: To evaluate the effectiveness of lifestyle intervention on well-being, occupation and social participation.

Methods: A randomized controlled trial was used. A lifestyle course in combination with physical activity (intervention group) compared with physical activity alone (control group). Both programmmes started three months post stroke and were held once a week for nine months at senior centres in the community. The Short Form Questionnaire (SF-36), addressing well-being and social participation was the primary outcome measure. Secondary outcome measures were the Canadian Occupational Performance Measure (COPM) measuring change in self-reported occupational performance and satisfaction; the Hospital Anxiety and Depression Scale consisting of two subscales (anxiety and depression); the Timed Up and Go (TUG) to assess mobility; and the Trail Making Test (TMT) A and B evaluating cognitive function. Assessments were performed at baseline and nine months' follow-up.

Results: Of 204 stroke survivors screened, 99 (49%) were randomized whereby 86 (87%) participants (mean (SD) age 77.0 (7.1) years) completed all assessments (39 in the intervention group and 47 in the control group). No statistically significant differences were found between the groups at the nine months' follow-up in the primary and secondary outcome measures. Adjusted mean differences in change scores in the eight subscales of SF-36 were; 'mental health' (+1.8, 95% CI -4.0, +7.6), 'vitality' (-3.0, 95% CI -9.6, +3.6), 'bodily pain' (+3.3, 95% CI -7.8, +14.4), 'general health' (-1.6, 95% CI -8.4, +5.1), 'social functioning' (-2.5, 95% CI -12.8, +7.8), 'physical functioning' (+1.0, 95% CI -6.7, +8.6), 'role physical' (-7.1, 95% CI -22.7, +8.4), 'role emotional' (+11.8, 95% CI -4.4, +28.0).

Conclusions: Improvements were seen in both groups, but no statistically significant differences were found in the intervention group compared to control group. An intervention comprising regular group based activity with peers may be sufficient in long-term rehabilitation after stroke.

5. Discussion of the main findings

The overall aim of this study was to develop, implement and evaluate a group based person-centred lifestyle intervention on well-being, occupation and participation for older adults following stroke. The rationale for this study was that many older adults, after stroke, report anxiety, depressive symptoms, social isolation and reduced well-being up to five years after stroke. The literature searches indicated that there seem to be a paucity of psychosocial interventions which go beyond personal care. Our study is a contribution to address this paucity by undertaking the development, implementation and evaluation of a psychosocial intervention for older adults with mild to moderate stroke.

Concerning the evaluation of the intervention no statistically significant effects of the lifestyle programme as a supplement to physical activity were found. These findings were unexpected particularly because this intervention was inspired by the Lifestyle Redesign® which demonstrated positive effects on health, function and quality of life domains during a nine months intervention for older adults [43]. A replication of this study also demonstrated beneficial effects for ethnically diverse older people (mean age 74.9 $\pm$7.7 years) and it had the potential to help reduce health decline and promote well-being after six months intervention [111].

An interesting finding in our study was that the participants showed lower scores at baseline in seven of the SF-36 subscales compared to the general Norwegian population. After nine months, several of these differences had disappeared, which illustrated that such improvements in health and well-being can be seen in the later phase after stroke.

The main findings will be discussed related to the aims of the intervention, psychosocial interventions, evaluation of the study design and methods. Finally challenges concerning the use of RCTs in evaluating psychosocial interventions will be addressed.

5.1. Occupation, participation and well-being

In line with the aim of the lifestyle intervention occupation, participation and well-being have been addressed particularly through the process of developing and implementing the programme. Concerning the development of the intervention, the application of the Canadian Occupational Performance Measure (COPM) as the individual needs assessments revealed a great variety of occupational issues. The participants prioritized occupations of importance which were related mainly to active recreation, household and community management,

mobility and socialization. These findings were further utilized in the lifestyle group sessions. The participants were invited by the group leaders to share, choose and decide the intervention content in interaction with the group participants. The intervention content showed a great variety which indicated that the themes were developed in line with the participants' choices and desires and related to occupations they found of importance (paper II). This study suggested that COPM used as an individual needs assessment and further utilized in group sessions, enhanced participation and illustrates a person-centred approach. These findings are in line with a study by Wressle et al. which demonstrated that COPM contributed to active participation in the goal formulation process and improved involvement in the rehabilitation process [112]. Person-centredness is also documented to better recall goals and contributed to the participants' feeling more involved and able to manage more everyday occupations after rehabilitation [113]. A person-centred approach is also suggested to improve occupational rights related to experience meaning and enrichment in one's occupations; to participate in occupations for health and social inclusion; to make choices in daily life; and to receive equal privileges for diverse participation in occupations to reduce occupational injustice [58]. Engaging persons in taking charge after stroke to promote self-directed rehabilitations has been demonstrated to improve health-related quality of life and reduced dependency and strain on carers. Thereby supporting the concept of the importance of being open to ideas from the person and their family [114] who also can be seen as a support for person-centred interventions.

The methods (self-reflection, peer exchange, didactic presentation and performance of occupations in real contexts) applied in the lifestyle group sessions seemed to illustrate participation in different ways. Findings in paper II demonstrated how the group participants addressed participation by sharing experiences, inviting the group to join a guided walk in the local area, invitations to coffee in one of a participant's home, helping others and doing occupations together. Findings from the focus group interviews created awareness of the participants' competencies and demonstrated how they in different ways demonstrated participation and engagement in adaptations to enhance control, autonomy and occupational balance after stroke particularly by addressing enjoyable occupations (paper III). In this way participation was related to occupations that the participants found meaningful. The term 'participation' has been explored among individuals living with chronic pain and also revealed that participation can be experienced as taking initiative, making choices, doing something physical, doing something social and doing something for others [115] which also is

addressed in our study. The findings give support to the work by Vik et al. who addressed the importance of understanding participation as a dynamic engagement ranging from individual agency, including decision-making, choosing, and acting in daily life, to letting life itself be the agent experienced by older adults in home-rehabilitation [116]. They also suggested that participation in occupations is social and contextual and that occupational therapists need to tune into the persons' unfolding experiences to be person-centred. In paper I older adults experiences of attending a senior centre can be related to participation interpreted in a Western cultural context. This study addressed experiences of participation related to an ambiguity between a 'sense of threat' and a 'sense of thriving' and demonstrated that 'participation' can create negative values. The findings in our study seemed to address a broader understanding of 'participation' compared to the definition 'involvement in a life situation' given in the International Classification of Functioning, Disability and Handicap [33].

The theoretical framework (occupational science, the Canadian Model of Occupational Performance-E and occupational justice) applied in this study created increased awareness of the relationship between the older adults' occupations, well-being and participation after stroke.

5.2. Psychosocial group interventions after stroke

Our study did not demonstrate any significant effect of the lifestyle intervention. A group intervention, led by volunteers, addressing going out regularly and meeting with peers may be sufficient in the long-term rehabilitation after stroke to enhance social activity and participation. These findings inspired me to conduct a new literature search (September 2011) to identify group interventions after stroke in the community. Eight studies evaluating the effectiveness of group interventions after stroke were identified (appendix 2). Additionally, a systematic review was identified which raised the importance of group intervention targeting social isolation in older people with focus on social activity in groups and older people as active participants [50]. Dickens et al. demonstrated that 79% of the group based programmes evaluating the effectiveness of social interventions for alleviating social isolation reported on improvements while only 55% of individual programmes reported on improvements [50]. This justifies further focus on group interventions to reduce social isolation.

The eight identified studies were mainly randomized controlled trials with participants at the median age from 62 to 72 years. The duration of the interventions varied from three weeks up to eight weeks. One study offered a motivational interview and one lifestyle class [117].

Examples of the content of the interventions addressed were: self-management, self-efficacy, education, physical activity, social activity and motivational interviews. The interventions were mainly conducted by health professionals and three studies involved collaboration by volunteers or peers [118-120]. Three of the eight studies were conducted in Australia. One study showed that the self-management course in groups (such as education, engaging in activities, adopting healthy behaviour, managing negative impact, taking an active role in their own health) failed to influence mood, thinking, social roles and self-efficacy which was unexpected. However the intervention group avoided decline while the controls reported decline during the first year. The authors suggested that it is possible that merely being offered an intervention, exposed to others, knowing that ongoing group support is available may be sufficient [121]. Another study in Australia demonstrated that activity, education and social interaction for stroke survivors and their carers might improve health related quality of life and physical functioning. However there were insufficient participants to achieve any possible level of statistical significance [122]. The third study in Australia demonstrated in a trial (n=143) that a Stroke Self Management Programme (SSMP) included greater participation and completion rates [118]. Two of the eight studies were carried out in Canada. One study compared a 'Moving On after Stroke' (MOST) programme with a standard education programme 'Living with Stroke' (LWS). The study suggested that social support was an important benefit in both programmes and that MOST participants improved significantly on two of the five outcome measures which were related to reintegration to normal living and an activity specific balance scale. The importance of psycho social factors emerged [119]. The second study in Canada compared an educational counselling intervention with lifestyle classes and demonstrated significant differences between groups on stroke knowledge; however no differences identified risk factors [117]. A study in China showed that a group based educational programme helped stroke participants to integrate their knowledge into their real lives [123]. In the United Kingdom, Mead et al found that an exercise training programme compared to a relaxation programme led to significantly greater benefits in aspects of physical health.[124] . A further study in United Kingdom showed that a community-based scheme for stroke survivors was successful in improving physical integration when compared to standard care [120]. To summarize, these studies are promising, but further evaluations are needed. A systematic review also suggested that benefits seem to be gained from self-management programmes; however, the optimal format of delivering these interventions is not yet clear. Timing post-stroke, delivered by health professionals or lay bodies have to be

further explored [125].

In our study the physical activity groups were conducted by volunteers. They expressed that they enjoyed conducting groups, being in a research project and feeling useful. After the intervention period was closed, one volunteer expressed that she very much would like to continue to conduct groups. This inspired reflections on the importance of volunteering. Evidence has been shown of reciprocal relationship between volunteering and well-being, however further needs for research were raised [126]. A systematic review suggested that lay-led self-management education programmes may lead to small, short-term improvements in participants' self-efficacy, self-rated health, cognitive symptom management, and frequency of aerobic exercise (the mean age of study participants ranged from 44-72). There is currently no evidence to suggest that such programmes improve psychological health, symptoms or health-related quality of life, or that they significantly alter healthcare use. Future research on such interventions should explore longer term outcomes, their effect on clinical measures of disease [127].

5.2.1. Involvement of families and carers

Social support and family ties are strong predictors of recovery after stroke [36]. Due to that our lifestyle programme was person-centred; carers were involved in different ways. Some groups included their families while others were not interested. Some participants expressed: 'It is nice to be in this group, because here I can talk about things that I don't want to bother my family with'. This contributed to an understanding of why some participants did not involve their families. Other participants invited their spouses to join some of the outings such as those to the cinema/theatre/opera/museum. This was discussed at the group meetings prior to the outings. A recent study has shown positive effects of intervention designed to engage both the patients and their families in the process of recovery aimed at promoting self-directed rehabilitation [114].

5.3. Evaluation of the study design and methods

The main strength of our study was the pragmatic randomized controlled trial design comparing groups to evaluate the effectiveness of the intervention. A population of older adults with mild to moderate stroke was randomly allocated to control or intervention group to reduce bias. Recommended guidelines [51;73;75] were followed and the study was reported in line with CONSORT [91]. In line with these guidelines the aim was to strive to demonstrate complete, clear and transparent information on the study's methodology and findings. To meet the complexity, qualitative, interpretative and quantitative approaches were applied through the process of development, implementation and evaluation of the intervention. Another strength was a high attendance rate in both the control and the intervention group. The median number of sessions attended in the physical activity groups was 20 (6-29) among controls and 23(8-29) in the intervention group, and the median number of lifestyle course sessions attended was 28 (23-31). All the follow up assessments were done by the same assessor who was 'blinded' for the group allocation. Masked conditions were maintained for the assessments of 86% of the participants.

5.3.1. Sample size and outcome measures

There were some limitations. Firstly, the sample size was relatively small. However, all effect estimates were close to zero, and it is unlikely that a trial with higher statistical power would have detected any differences. Ceiling and floor effects in the outcome measures may, however, have masked potential effects of the intervention. The primary outcome SF-36 showed both ceiling and/or floor effects among more than 15 % of the responses at baseline as well as follow-up in the subscales of bodily pain, social functioning, role physical and role emotional. This might have an impact on detecting differences between the groups [128]. Hagen et al also found that sensitivity to change in SF-36 was poorer in later stages compared to the early post-stroke phase [129]. The lifestyle programme is a complex intervention and possibly this intervention has other effects which are not detected by the SF-36. The SF-36v2 might have been more suitable particularly because some questions are made easier to understand and the interpretation has been greatly simplified with a norm-based scoring where each scale has the same average (50) and the same standard deviation (10) [130]. However, the SF-36 is still the most frequently used generic measure in clinical trials evaluating patient-reported outcomes[131]. There is no consensus about outcome measures in evaluating complex

intervention in long-term after a stroke [132]. The study participants showed lower scores at baseline in seven of the SF-36 subscales compared to the general Norwegian population. After nine months several of these differences had disappeared, which illustrates that such improvements in health and well-being can be seen in the later phase after stroke. This demonstrated that SF-36 could detect changes which are not necessarily related to the aim of the intervention.

Concerning the secondary outcome measures they did not detect any differences between the intervention and control group however they demonstrated improvements in both groups.

5.3.2. The participation rate in the programmes

A total of 204 people with stroke were invited to participate in the trial. One hundred and fifty five agreed to participate in the baseline evaluations, however only 99 (49%) accepted participation in the programmes. The context of this study was senior centres which could have influenced the participation rate. Older adults attending a senior centre can perceive the centre as a meeting place only for very old, frail and sick people. A 'sense of threat' can be revealed and they might make distance in relation to those they perceive as frailer than themselves (paper I). This could have had an impact on the participation rate. However some participants expressed different reasons to refuse participation such as; 'groups are not my cup of tea', 'I am too busy' or 'I have no time because I have to take care of my spouse'. Thus factors associated with our participants' choices to participate are explored in another study.Attrition seems to be higher in older populations [133]. To reduce attrition we chose inclusion in line with 'opt-out' recommended by Junghans et al.[134]. 'Opt-out' means that the participants' consented to be followed up by further communication until they actively chose to withdraw [134]. The participants were followed closely with home visits and repeated phone calls to motivate them to attend at least one meeting in order to find out for themselves if the programme was a desirable service. At the same time we used no pressure and refusal was accepted without questions.

5.3.3. Delivery of the lifestyle programme and the physical activity

There were similarities in delivering the programmes. Both the intervention and control groups were offered transport, phone calls prior to each session and weekly group sessions meeting with peers over nine months. Experienced engaged group leaders were used in both groups. The context for both the intervention and control group was senior centres which are

open meeting places emphasizing social contact. Many participants regardless of group allocation, used the services provided at the centres and had a cup of coffee or dinner before or after the sessions. This might have enhanced the social interactions, occupation and well-being for participants in both groups. Many participants from both groups stated that they enjoyed participating, and they addressed the importance of enthusiastic group leaders. Participation in the control group as well as in the intervention group might have contributed to an improved psychosocial functioning and increased motivation to take an active role in the recovery process after stroke [135]. These similarities have probably influenced the finding of no differences between the groups. The studies in the USA which demonstrated positive effect were designed in a different way. The Well Elderly 1 applied three groups: intervention, social activity and no-treatment [43]. The participants in The Well Elderly 2 were randomly assigned to the intervention or no-treatment control condition which was justified based on findings from the Well Elderly 1 of no differences between the social activity group and a no-treatment control group [111]. When planning our study we decided to offer all the participants an intervention. The participants were included from hospitals and to invite them to participate in in a study with nothing to offer was found difficult due to ethical considerations.

Although many similarities between the intervention and control group were revealed there were differences as well. The aims of the group sessions differed. While the lifestyle sessions emphasised self-reflections, self-management, doing occupations together chosen by the participants and performed in natural contexts, the physical activity sessions addressed different physical activities together to improve general physical function. The group leaders' background was different. The lifestyle sessions were led by professionals (occupational therapists): the physical activity sessions were led by volunteers from various backgrounds (retired physiotherapists or volunteers at the centres interested in general physical activities).

5.3.4. Validation of the findings

The trustworthiness, the strength and the transferability of knowledge are often discussed in relation to reliability, validity and generalization within the social science [81]. I will mainly address validation related to the qualitative and quantitative approaches in our study. Validity is not quite the same in the two types of approaches.

Qualitative and interpretive approaches. In social science validity is pertained as to whether a method investigates what it purports to explore [81]. Validity in qualitative research is understood as a continual process of validation of interpretations and concepts and is basically

seen as an ongoing dialogue. Validation in this sense is not defined to a separate stage but include all stages from the first thematising to the final reporting [81]. The ongoing interpretive process and the researcher's positioning were described particularly in paper I and paper III which is of great importance in these approaches. The Western consumer culture was applied as a context for the process of interpretations. Generalization is created through how the results are presented and how the results are received [136].

Statistical approaches. In a positivistic approach validity is related to whether you are measuring what you think you are measuring [81]. Three types of validity are addressed; concept validity, internal validity and external validity [137]. Concept validity is associated with the concept being studied and whether the problem being studied was suitable and adequate and, accordingly, several variables and tests are used [137]. Concept validity assesses the degree to which the data reflect the variables that we wished to study [137]. In the randomized controlled trial the concept studied has been described and reliable outcome measures were applied. However, as raised in paper IV, it may be possible that the lifestyle intervention has other effects which are not detected in the primary outcome SF-36. Internal validity concerns the conclusions drawn from the study and is associated with valid inference in the population we have studied and bias may occur related to: sample selection bias, information bias and statistical confounding [137]. Our study showed no statistical differences between the control and intervention group which indicated that the H_0 hypotheses was sustained which implies a risk of type II error due to the sample size being relatively small. However, the effect estimates were close to zero and it is likely that a trial with higher statistical power would not have detected any differences. Information bias occurs when the participants in a study report incorrectly or when the information registered is flawed in other ways [137]. To reduce this information bias only two persons did the registrations (the researcher and the research assistant) and also if there were some missing, the patients were contacted Additionally there was external monitoring of the data (Appendix 3). Concerning statistical confounding we applied reliable outcome measures and applied statistical tests which were presented with effect estimates adjusted for confounding , confidence interval and p-values[137]. Randomized controlled trials are often said to have high internal validity due to randomization and blinding to avoid association between treatment and external factors that may influence the result (confounding). However, a drawback is that they have low external validity which implies that the results cannot necessarily be generalized [138]. External validity concerns generalization and depends on design, population and statistical models [137].We have strived to present

conclusions explicit such that the reader may assess external validity[137]. In this study a selected population was used and therefore the findings cannot be generalized to a broader population of older adults with stroke.

5.3.5. Challenges in using RCTs to evaluate complex psychosocial interventions

When designing an RCT for evaluating psychosocial complex interventions there were some methodological obstacles experienced and discussed in our study. In a Western society which requires evidence for interventions offered within the health and social care we need to evaluate effectiveness of psychosocial intervention after stroke. However there are currently discussions going on as to whether RCTs alone will be appropriate for evaluating complex interventions particularly because most trials have evaluated the effects of a single intervention such as a drug [75]. This raises the importance of combining and finding a balance between different research approaches and sources of knowledge. Integrating qualitative and quantitative methods is suggested to create a more comprehensive understanding of well-being following stroke [139]. However, the use of qualitative methods alongside RCTs in complex healthcare interventions remain uncommon and have been mainly carried out before or during the trials with few studies used to explain trial results [140].

Although qualitative methods were applied in this study in developing the intervention, a qualitative evaluation after the intervention was closed was not planned. However, my experiences during the nine months intervention were coloured by many participant who expressed their satisfaction with being offered the group intervention and being a part of a research project. We assumed after a while that the chosen study design, outcome measures, similarities between the intervention group and control group would probably not be sufficient for detecting the ongoing processes in the groups. This assumption was facilitated by one of the participants who said 'Please do not let us answer all these surveillance questions, we would rather like to tell and share our experiences of participating in the group'. As suggested by Lewin et al. qualitative approaches can increase our understanding in several ways to the development and evaluation of complex interventions [140]. Consequently a Master student was invited to conduct a qualitative study to increase knowledge of some participants' experiences of participating in the lifestyle groups. These findings created supplementary knowledge of the participants' experiences in attending the lifestyle intervention. Six participants were interviewed. Social activity, feelings of belonging, meeting people in the same situation and opportunity to exchange experiences were emphasised by the participants.

This study suggested that the participants used their group participation as a tool in their individual process in collaboration with peers of making adaptations, increasing control, autonomy and well-being in their daily lives after stroke [141]. These findings contributed to increased knowledge of the participants' experiences of being in the lifestyle group sessions. The results from the interviews seemed to reveal a process of adapting to everyday life after stroke which was not detected in the statistical analysis.

Challenges in translating findings (from RCTs) into practice have been raised since the design provides evidence of effectiveness for the 'average patient' while in practice the clinician will be interested in what will be effective for the specific patient and not the 'average' [142]. In this study a tension and contrast has been experienced between 'one size fits all' to the tailored individual intervention. In the process of developing and implementing the intervention each participant has been addressed. In the evaluation we have focused on what can be effective for a population of older adults with mild to moderate stroke. Additionally the interviews of six participants in the lifestyle groups emphasised the individual participant's experiences [141]. Also we have strived for transparency through detailed description of design, methods, analysis and findings.

5.3.6. Challenges in combining different methods

Using different approaches to develop, implement and evaluate complex intervention can provide complementary knowledge which is supported in literature [76;139]. Although the combination of different methods in evaluation of complex interventions is recommended [75;139] the use of multiple approaches in a single project has been seen as considerably controversial [143]. This stems from the perception that each approach has different ontological and epistemological paradigms. Quantitative research falls into a positivistic paradigm where the world is generally stable and predictive, with conforming norms and patterns. A qualitative approach, on the other hand, may fall into an interpretive paradigm which assumes that the world is in a dynamic state of flux, with multiple subjective realities. Clark stated that reality is something that can be measured and generalized and also something unique to each individual [143]. It has been challenging in using different approaches in this study. My experiences are 'coloured' by my continuously striving for changing and adapting my work to the context of the different approaches creating knowledge which is complementary and at the same time being in two different worlds. I have met a challenge related to that in a Western cultural context the positive valuation of RCTs might have contributed to devaluation of

qualitative and interpretive approaches. The application of RCTs has increased important knowledge in clinical medicine regarding which interventions are effective, which are ineffective and also which interventions can create harm. However the positive valuation of RCTs and systematic meta analyses has systematically devalued the knowledge based on clinical experiences [144].The importance of combining different methods and not favorise either of them was raised [144]The importance of combining different methods including patients' perspectives and clinical expertise and not favourises either of them is also expressed by Sackett: 'Evidence-based medicine is the integration of best research evidence with clinical expertise and patient values' best integration of best practice' [145].To meet the future populations' needs I think it is of great importance to apply different approaches and striving for equal valuations. O'Cathain enlightened that health workers are increasingly using both qualitative and quantitative designs stated that the main challenge is to combine the results by using techniques for integrating the analysis in mixed methods research. This is suggested to generate further understanding from the research [146]. Although different approaches have been used in our study the next step could be to further integrate the interactions between the qualitative and quantitative components [146] thereby embracing differences instead of imposing homogeneity [147].

6. Conclusions and future suggestions

In conclusion, a lifestyle oriented occupation based group intervention as supplement to a physical activity programme showed no additional effect on well-being, occupation and participation for older adults after stroke. However, improvements were observed more than one year after stroke. Interventions to address going out regularly and meeting with peers may be sufficient in the long-term rehabilitation after stroke to enhance well-being, occupation and social participation. Further evaluations of the effectiveness of group based, person-centred lifestyle oriented programmes after stroke are warranted particularly to enhance social participation and well-being.

There are challenges in designing studies to reveal effects. More conclusive evidence is required before decisions are made on the provision of lifestyle oriented interventions in rehabilitation after stroke. Rehabilitation is not cheap and depends upon learning which takes time. It also depends on personal interactions between rehabilitation staff, the patient and their families. The more complex the patient's situation, the more resources are likely to be needed. The measures of patient complexity and the measure of complexity of the rehabilitation process are still poorly developed [148].

Clinical implications

- A lifestyle group intervention as a supplement to physical activity group showed no additional effect on well-being, occupation and social participation for older adults after stroke.

- The participants with stroke showed improvements on SF-36 during the nine months intervention which indicated that their health related well-being and activity were likely approaching that to the general Norwegian population adjusted for age and gender.

- Regular social group activity and meeting with peers are recommended in the later phase following stroke.

- Senior centres seem to be a sufficient arena for creating social relationship and social activity among older adults.

- Older adults with stroke can perceive the stroke as a threat to social inclusion, dignity and control of everyday life. At the same time they reconstruct occupational balance by addressing enjoyable occupations in a variety of ways.

‘Adversity draws men together and produces beauty and harmony in life's relationships, just as the cold of winter produces ice-flowers on the window-panes, which vanish with the warmth.’

Søren Kierkegaard, Danish philosopher (1813 –1855)

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Papers I -IV

I

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'I am not *that* old': inter-personal experiences of thriving and threats at a senior centre

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ABSTRACT
The high cultural valuation of youthfulness and fitness in the mass media and more generally in western consumer society is the contextual frame for this study. It examines older people's attitudes towards their own ageing and towards people who are older or frailer than themselves. Participant observation was conducted of the attitudes, actions and interactions of the users of a senior centre in Norway. The users held two sets of attitudes that led to quite different activities and actions at the centre. On the one hand, they saw the centre as helping them 'thrive', which was associated with involvement in the community and participation in the structured daily activities to promote the senses of belonging and being useful. On the other hand, some perceived the centre and particularly the other users as 'threats' – as reminding them that they were getting old and increasingly vulnerable to sickness and disability. To some, the centre was for old people with disabilities, and they used subtle strategies to distance themselves from this group. Some users' attitudes and behaviour were in tension: they wished to participate in the valued activities but also to distance themselves from frailer users, while not denying their own ageing. The distancing strategies and behaviour amounted to age discrimination in interpersonal relations and interactions at the centre. This behaviour accepts rather than challenges the cultural valuation of youthfulness and the negative representation of old age.

KEY WORDS – ageism, consumer culture, notion of ageing, seniors' experiences, youth orientation.

Introduction

This article critically examines questions about what it means to grow old in today's western consumer culture that promotes a youthful orientation and ageism, and about how older people live and relate to these ideals.

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The aim is to illustrate what it means to older people to be 'old' and 'not old'. Evidence is drawn from participant observation of the interactions of the users of a senior centre in a Norwegian city. The theoretical and methodological premises are that the cultural and societal contexts of the communal setting are a useful lens for analysing and understanding the perceptions and behaviour of older people.

The last 20 years have seen increased research on old age, but most has focused on meeting the rising need for health-care and social services (Andrews 1999). The medical and needs perspectives generally focus on longevity, autonomy and independence in older age (Bowling 2007). While the dynamics of ageism and the denial of ageing have been well documented, little attention has been paid to the conflicting messages about what it means to be old and how the ensuing contradictions are implicated in a process by which individuals distance themselves from 'the old'. Recent studies of the personal experience of ageing have emphasised the difference between 'being old' and 'feeling old' (Daatland, Solem and Valset 2006; Torres and Hammarstrom 2006). Hurd (1999) explored the ways in which women at a senior centre in Canada actively and interactively constructed and negotiated age categories, by distancing themselves from those whom they perceived and considered as 'old'. Further research is needed into the interactions between beauty standards, gender, ageing, physical characteristics and perceived desirability, not least to situate personal ageing as a central constituent of contemporary culture. The article describes successively the setting of the study, the participant observation method, and our analysis and interpretation of the interview and observation data.

Senior centres in Norway

Senior centres are voluntary meeting places that provide social contact and the prevention of loneliness and isolation for people aged 60 or more years. They explicitly seek to promote health and prevent disease. In Norway there are approximately 330 senior centres, and most are run by voluntary organisations (Helse og Omsorgsdepartementet 1996; Slagsvold, Daatland and Guntvedt 2000). Around 40 to 55 per cent of the older population in Norway are registered as users (Pettersen and Laake 2000, 2003). A literature search in June 2007 in PychINFO, MEDLINE and PubMED identified no recent studies of users' experiences, communication and interactions at the senior centres, but there have been a few evaluations of Norway's senior centres. The most recent in 2006 was a survey of 2,764 users at 41 centres in the City of Oslo. The findings showed that the senior centres are important in the users' lives, and that there was

a positive relationship between the age of the user and the importance that they attached to their visits (Helse-og velferdsetaten 2006).

Western consumer culture and the personal experience of ageing

Understanding the role of culture in contemporary society is crucial to an understanding of the position of older adults (Tulle-Winton 1999). The various cultures of ageing each have their own representation of old age (Gilleard and Higgs 2000). The standpoint of this paper is that culture is a dynamic system in which human beings weave self-made meanings, and that these are created, negotiated, contested and changed through interactions with others and the environment. The culture is complex; it has been described as 'the air that we breath' (Geertz 1973; Thorsen 2005), and it is continuously in flux and contradictory, which gives rise to different meanings. Many have seen contemporary western culture as first and foremost one that creates a general expectation of staying young (Sassatelli 2007), in contradiction to the unavoidable fact that we all age day by day. If the consumer culture has been created mainly by the media, arguably it is reinforced by health-care and social policies that promote healthy lifestyles and encourage 'active ageing', physical activity and good nutrition.

'Go-go' and 'no-go' images

In the western media, different versions of personal ageing are presented, but the most influential convey a dichotomy between 'go-go' and 'no-go' attitudes and behaviour (Blaikie 2006; Danielsen and Valset 2004; Mountain 2004). Older people are represented as an increasingly affluent, active group of people, of whose concerns politicians should take note, and from which more workers might be found to sustain the economy (Mountain 2004). Older adults are also seen as creating 'senior markets' to which 'successful marketing to the 50+ consumer' is directed (Sawchuk 1995). In line with the 'go-go' images, the media delight in exceptional stories of the abilities of very old people. On the other hand, there are also many representations of 'no-go' older adults, characterised by frailty, illness, dependency on health-care and social services, demeaned, and a social and economic burden to society (Blaikie 2006). These polarised images contribute to stereotypes and place older people in a social ghetto. The individuality of each older person is neglected and ageism is created (Featherstone and Hepworth 1995; Reynolds and Lim 2005).

Active ageing

Health and social policies have adopted the notions of 'active ageing' and 'healthy ageing', because they are thought to promote 'successful ageing' through healthy lifestyles, physical activity and good nutrition. The ambition is to help people remain independent and active into old age (World Health Organisation 2002, 2006). The foci on active ageing, activities and occupation have been welcomed by occupational therapists, gerontologists and others concerned with seniors' wellbeing, but there have also been cautionary and critical responses to the wholesale promotion of 'positive ageing' in policy documents and the media (Andrews 1999; Laliberte Rudman 2006). Expositions of 'successful ageing' cite inconsistent definitions and promotional factors. Several studies have shown that older people believe that they have aged successfully even when they have disorders and functional limitations, which the medical perspective sees as markers of lack of success (Bowling 2007). 'Active ageing' has taken on a moral significance in the understanding of what it is to age well. Promoting an expectation of good health and functioning in old age could limit the understanding of successful adjustments to ageing and of appropriate existential priorities in later life (Biggs 2006).

Resisting the ageing process

People use various overt and subtle strategies to resist, deny and postpone the ageing process (Featherstone and Wernick 1995; Gilleard and Higgs 2000; Tulle-Winton 1999). Promoting the ideal of youthfulness is not a new historical phenomenon and has been expressed variously at different times (Öberg and Tornstam 2001). Today, there is increasing use of clothing, diet and cosmetics to mask the visible evidence of ageing. In western society, the body is often regarded as both symbol and product, and a homogenised ideal of body and beauty based on consumer values has wide currency. A dominant media message is that nobody needs to live with an unsatisfactory body. The focus on the body may create vulnerability and anxiety, however, and raises issues of the subjective understanding of the body (Engelsrud 2006). The value of cosmetic surgery seems to be widely accepted by women, and to be increasingly considered by men. Its use represents an attempt to conform more closely to a cultural standard of beauty and even of identity (Askegaard, Gertsen and Langer 2002; Heyes 2007). Consumer culture promotes solutions that draw upon medical and technical expertise in featuring active youthful older adults, which can be regarded as a continuation of the long-established tradition of interest in rejuvenation and longevity (Featherstone and Wernick 1995).

If one's body has become a symbol of one's identity, being fit reflects the person's willpower, energy and self-control in achieving the cultural norm of a 'youthful' old age. An approved strategy has become to pursue fitness activities to change body shape, instead of passively resigning oneself to losing shape and vigour (Öberg and Tornstam 2001). A third way of dealing with growing old is to distance oneself from the old body with thoughts and expressions such as, 'I am not as old as I look', and 'Inside I feel young' (Featherstone and Wernick 1995; Öberg 1996). Studies in Sweden and Norway have found that about 70 per cent of 40–85-year-olds would like to be 10 or more years younger than their chronological age (Andersson and Öberg 2006; Daatland, Solem and Valset 2006; Öberg and Tornstam 2001). Youthfulness, physical strength and fitness seem to be regarded as age-independent and a criterion of social value (Andrews 1999; Biggs and Daatland 2006; Thorsen 2005). The present culture creates a tension between the inevitability of the decrements of ageing and youthfulness. The negativism of the former is exaggerated by common stereotypes of old age and older people, which stigmatise older people in society, and by which ageism is created and maintained (Danielsen and Valset 2004; Featherstone and Wernick 1995; Hurd 1999). The Norwegian composer Halvdan Sivertsen expressed the tension between the idealised ambition and awareness of its unreality in the song, *We Will Live Long, But We Will Not Grow Old* (Sivertsen 1994).

The participant observation study

The senior centre

The senior centre for the study was selected in consultation with one of the main organisations that run them, the Norwegian Health Association. Its mission statement focuses on the promotion of 'thriving, security, social contact and networks, stimulating experiences in daily life, good food, inclusive atmosphere, information and guidance regarding personal economy, nutrition, health, activity and assistance in practical activities'. 'Thriving' is emphasised and in this context associated with 'good health' and 'subjective well-being', consistent with terms used in social gerontology (Slagsvold 2000). The centre has 3.5 permanent posts – the manager, a cook and two assistants. In addition, more than 40 pensioners volunteer their assistance, from once-a-month to almost daily. The centre is near the centre of a city of around 500,000 and accommodated in a well-restored, old Suisse villa. One entrance is accessible using stairs and another from a ramped path. In the entrance hall, there is a notice board with information on the programmes for the day, the week and the month. At one

visit, the following messages were prominent: 'Welcome to the senior centre. The door is open from 8 am to 3.30 pm on Mondays to Fridays', 'Today's meal is homemade meatballs', 'Welcome to today's lecture, *Laugh and Prolong Your Life!*', 'Every Monday [there is] Nordic walking', 'Senior dance for active seniors', 'Welcome to the handicrafts group' and 'Welcome to the music-café on Sunday, once a month'. The senior centre therefore offers many cultural, hobbies and exercise activities, and several personal services, including catering, hairdressing and pedicure (Lund 2005).

The participants

The participants were drawn from the 2,339 registered community-dwelling users and volunteers aged 60 or more years; they all lived locally. The number of registered users who visit the centre more than twice a year has increased from around 500 in 2003 to 636 in 2004. Women are the main users and only 19 per cent are men (Lund 2005), which is in line with women's higher average life expectancy.[1] The age profile of the users in 2004 was older than the general elderly population: the average age was 77 years, and 44 per cent were aged 80 or more years. Each day 20 to 70 seniors visited the centre. Some attended for a specific reason, such as to visit the hairdresser, for the French course, to have a meal or to meet people. Others visited the centre regularly and talked with people they met every day. The volunteers undertake many tasks at the centre, for example managing the café, doing office work, welcoming new users, or organising the bridge or computer groups (Lund 2005).

The participant observation method

Participant observation was used to gather data about the seniors' communal activities and interactions at the senior centre, and their lives and stories outside the centre have been considered only indirectly through what they said.[2] To approach an understanding of the meanings that the users of the centre had of its activities (Denzin and Lincoln 2005), the researcher (AL) attended the centre for about 100 hours spread over 17 days through three months. Field notes were written at the centre and carefully recorded at the end of each day. The researcher worked as a volunteer, which enabled interactions and collaboration with the seniors (Järvinen and Mik-Meyer 2005). Instead of just observing, the researcher participated in the activities, such as serving meals, activity groups, the management of the café and office work. It should be recognised, however, that the researcher was not of the same age or in the same social situation as the senior users. She had a dual perspective that fluctuated

between distance from and closeness to the senior users, comparable to an apprentice in the workplace (Wadel 2002). The centre's activities were unfamiliar to the researcher, which created many opportunities to ask questions and learn from the users, and encouraged the sharing of experiences through 'doing' and 'saying'. The researcher interpreted the shared experiences by applying her occupation-focused approach that was sensitised to the ways in which the seniors both raised control over their environment and used inter-personal interactions to improve their wellbeing (Wilcock 2006).

The analysis of the data

The process of analysis began while developing the research questions and continued as data were gathered (Denzin and Lincoln 2005; Fangen 2004; Wadel 2002). The field notes were categorised as 'observation notes', 'theory notes' and 'methodology notes' (Fangen 2004). The concerted search for understanding and system in the data involved repeated selections from the three categories of notes and iterative comparisons and changes of perspective. The researcher sought to differentiate the way the material was created from her own experiences and interpretations. Interpretations were closely discussed with the second author (GE). The analysis identified various themes in the seniors' expressions about personal ageing and growing old. In deciding the labels for the themes, terms close to the seniors' vocabulary were preferred. 'Thriving' strategies were emphasised and described as such by the users. We defined the 'thriving' strategies as those that referred to or engaged with 'a sense of community', 'the rhythm of daily life' and 'feeling useful'. The notion of 'thriving' in these senses is close to subjective wellbeing (Slagsvold 2000; Thorsen 2002). On the other hand we found that 'threat' strategies were actualised and described in subtler ways. We found that the informants who distanced themselves from the centre and from other attenders connected these thoughts with striving to 'stay young'. We show how distancing strategies were used both in the users' conceptualisations of the senior centre and in their relations and interactions with others.

Strategies to promote thriving and to engage with a sense of community

Many users expressed their appreciation of the services offered at the centre and of the opportunities to meet other people. As one woman said, 'we have a nice time ... as human beings, we are created for community [social beings] which is particularly important here, since many of us live alone'. Belonging to the centre's community was expressed by using 'we'.

As one woman said, 'we will sit here until someone throws us out'. Another remarked, 'this (centre) is like our second home'. The way the users talked about the centre referred to both emotional and practical dimensions of belonging and community. For example, in the café there is one table where men regularly gather, and another where women sit. One of the men said, 'It is very important with these tables, because we can sit together with people we know'. The significance of the social contact was commented on by many users. One couple that had been married for more than 60 years emphasised the value they attached to the social network. The wife said, 'one of us will die first, and it can be difficult to be alone without people you know and can talk to'. Another user said, 'when you live alone it is important to get out and meet other people'. One woman said, 'I don't have any children, and I have been a widow twice and that is the reason why it is important for me to be here'. These users created meaning in their lives from being part of the social group at the centre, and by acting and interacting with each other. They were conscious of the importance of social contacts and of the sense of community and explicitly related them to a sense of thriving.

The value of rhythms in daily life

Visiting the centre helped many informants create a structure in their daily life, as was variously reported. One woman said, 'I started here when I was 78, when I stopped working'. Another woman said that she was keen to maintain a daily rhythm in her life and to be independent: 'I get up in the morning, dress, make breakfast, read the newspaper, tidy my bed and go to the centre'. Another woman who attended every day said, 'I go for my usual walk at half-past-nine ... I walk for about an hour every morning, and then I go to the centre'. Another user visited every Thursday because 'on Thursdays there is fish for dinner'. The 'fish days' created a weekly rhythm and continuity. One woman recollected, 'I started to visit the centre when I lost my husband ... and I have been here almost every day since'. There had been a change in her life but she had found new meaning through her visits to the centre. There were frequent mentions of the food and especially the dinner menu. One user arrived almost every day at one o'clock and explained, 'I visit this centre at dinnertime ... I do appreciate the homemade meal'. Every midday there was a long queue of people waiting to buy the excellent value, homemade food. One woman said, 'I belong to another local centre but I come here for dinner because they have such a good cook'. These examples reveal the importance to the users of a predictable and enjoyable rhythm in their daily lives.

The importance of feeling useful and productive

The senior users created different personal meanings from 'having something to do'. One woman who participated in the handicraft group said, 'it is nice to do something creative and what we make will be sold at the Christmas market to raise money for the centre'. A man added that 'they are doing something which is useful for the centre'. To feel useful was important for the volunteers. A female volunteer said, 'being a volunteer gives me something to do and I feel useful'. To feel useful, active and productive has a positive value for a person's identity and social regard. To summarise, the users of the centre gained a sense of thriving from experiencing the sense of community, from the rhythm of daily life and by feeling useful. There were also, however, contrasting expressions that can be interpreted as distancing or threat-avoidance strategies.

Strategies to avoid threats: the senior centre as a place for the old and sick

Not all saw visiting the centre in a positive light. The perceived threat of getting old manifested itself through several users' preconceptions and conceptions of the centre. A few said that 'visiting the centre is degrading'. When a woman was asked, 'are you old enough to visit the centre?' she replied that visiting the centre is undesirable because it is seen in the wider community as a place for 'old people', by which she referred to a stereotype of the socially isolated and frail. Some users' conceptions of the centre revealed that they also saw it as associated with 'being old', to which they implicitly attached a negative value. As one woman said, 'growing old has no status in society today'. The informants believed that the centre provides a service for 'old people', and because that group has low status, the centre's value is demeaned. Such preconceptions were revealed in one user's observation that, 'I think there are many people who don't know what a senior centre really is. They think it is a place for old and sick people'. These preconceptions are consistent with and may reinforce the stereotypical understanding of old people as sick and needy. Another user had an even more negative view: 'the centre is in a way the last stop before a nursing home. ... I do hope I don't need to move to a nursing home'. In these statements, the perceived threats of old age appear to be actualised and connected to the existential threat of dying.

For some users, however, their experiences at the centre changed such preconceptions. One woman instanced the effect: 'Previously I thought that the centre was not a place for me, because I thought people would only be talking about illnesses and negative things'. Another woman recollected that she was persuaded by a neighbour to visit the centre. She agreed to try it for one day and recollected that 'I was

surprised that I liked it here ... I have been here every day since'. Through her personal experience, her preconceptions of the centre were changed. A male user reported that some years ago, he was involved in changing the centre's name from the Norwegian name *eldresenter* [centre for the elderly] to *seniorsenter* [seniors' centre]. He said, 'we are seniors' and implied that the word *senior* conveys more respect for people's life experience than 'the elderly'. He associated 'seniors' with positive attributes, but in so doing distanced himself from 'the elderly' and the frailty it signified.

Striving for feeling and being young

One female user said, 'we are supposed to be young these days'. Distancing strategies from those who did not conform to this ideal were revealed in the ways that some users strived to feel and be young and in how some related to other users. Two examples are given. On visiting the centre for the first time, a man aged about 80 years asked, 'are there only so old people here? This is not for me'. He never returned, which might mean that his self-image was incompatible with his impression of the centre. His statement reveals that he saw 'others' as old but not like himself – he did not identify with the category 'being old', and responded by distancing himself from those that he perceived as 'older' than himself. The second example is of a woman who visited the centre once a month. One morning she whispered to the researcher, 'I feel too well to come here but I think the regular users need a breath of fresh air ... I am only 65, you know'. She mentioned her chronological age to distance herself from those whom she perceived as older. At lunchtime the same woman joined the regular users and talked about the pleasure she gained from a literature course at another centre 'because there are many young and vigorous participants in that group'. She thought a while, smiled and added, 'at least they feel young inside ... many of the users are more than 80 years-old!' She expressed the importance of being young, fit and healthy. She denied her own old age by using the distancing strategy that asserts that one feels young despite one's chronological age.

Distancing from conventional signs of ageing

One day a few regular women attenders were sitting at a table in the café. They projected a sense of community and were aware of the other users. Another woman was sitting alone in the café but then rose and shuffled back-and-forth buying a cup of coffee. The group at the table looked at each other and shook their heads. One said, 'Oh, why doesn't she lift her feet while walking!' This and other critical comments created distance between the group and those who 'shuffle', which was seen as a sign of old

age. Their reactions employed a negative symbol of old age and at the same time sustained a positive image of themselves. Another example of this strategy was when some regular users drew attention to a man who played the piano at the café. One remarked, 'he really plays nicely, even though he has a very crooked back'. This observation pointed to a (formerly common) sign of old age and reasoned that playing the piano well is inconsistent with being old – it was found remarkable that he played well in spite of a bent spine. The users had ways of commenting on each other that distanced themselves from those that they perceived to be frailer. This was revealed by remarks about a woman who used a wheelchair and at dinner was helped while eating by a personal assistant. One user said, 'It must be sad to be like that ... I do hope I won't get there'.

Some users visited the centre seldom, and it seemed important to them to define and rationalise their attendance. One woman said, 'Good morning; I am in a hurry, I am only visiting the hairdresser'. Another woman who was youthfully dressed in jeans said, 'I am only attending the French course. I feel we are younger in that group ... not necessarily in age but in behaviour'. These remarks might be interpreted as expressing personal strategies to resist seeing themselves as 'regular' users. They create distance from those that they perceive as older or frailer than themselves. Paradoxically, the strategy draws on a cultural stereotype that demeans old age and older people. The ideal celebrates a youthful body and indiscriminately places a negative value on natural ageing processes.

The actions and expressions of some volunteers distanced themselves from those whom they perceived as frailer than themselves. One woman said, 'it is important to volunteer because one day we will all be like those over there'. It is interesting that she did not yet feel 'that old', but recognised that ageing is inevitable and that one day she will be old 'like them'. She created distance from those that she perceived as 'old', yet accepted that she will join that category. This way of creating distance appears to deny that old age has been reached and supports the feeling of being young, but also alludes to the threat of one's own old age. The users' expressions showed awareness of the signs of normal ageing and created distance from the perceived threat of old age. These attitudes and expressions displayed a tension in an equivocal identity, as they denied old age and strived to avoid perceiving themselves or being perceived as old.

Our interpretation of the senior users' experiences suggests that their attitudes and behaviour contained contradictions between a sense of thriving and perceived threats from their participation, and particularly

from the social context and their interactions with others at the centre. The negative views manifested in the users' descriptions of their self-image as 'not yet old and frail', which tended to draw on and reinforce negative stereotypes of old age. The sense of thriving derived from involvement in a community, the rhythms of daily life and feeling useful. The feeling of being threatened was more insidious and derived from anxieties about and vulnerabilities related to ageing processes and finitude, which our interpretation suggests have roots in the negative valuation of old age in western consumer culture. Tension was revealed as the users deployed various strategies to distance themselves from those whom they perceived as frailer and older than themselves, while at the same time perceiving that their own ageing was inevitable.

Discussion

Thriving, health and well-being

The users' accounts of their experiences of and responses to the senior centre provided evidence of older people's diverse strategies for dealing with growing old in a consumer culture and revealed the insidious influence of the widely-held ideal of youthfulness. The users' positive accounts of the community, of belonging to a social network, accorded with one of the main objectives of senior centres, to foster social contacts that may prevent loneliness and isolation (Slagsvold, Daatland and Guntvedt 2000). Research has shown that it is valuable for older people to engage purposively in activities that avoid isolation, and that these may help maintain and promote health and subjective wellbeing, and even to prevent functional decline (Avlund *et al.* 2004; Jackson 1996). 'Health, wealth and social relations' are positively associated with wellbeing, quality of life and, in the users' terms, the sense of 'thriving' (Slagsvold, Clausen and Hansen 2006). The importance of the daily rhythm of activities was emphasised by some users. Visiting the centre regularly established continuity and a structure or rhythm to the users' daily activities. Structure and diversity in daily activities foster the senses of belonging and stability and help people live harmoniously with their own natures and with their environment and contribute to health and wellbeing (Jackson 1996; Meyer 1977; Thorsen 2002; Townsend and Wilcock 2004). Many of these associations were evident among the senior users' perceived benefits of attendance, were consciously recognised and manifested in their expressed motivations for attendance – these can be interpreted as personal strategies to promote thriving, health and well-being.

Strategies for resisting ageing

The senior users' distancing strategies from growing older revealed their perceptions of their own age. Some perceived themselves as young, despite their age and their awareness of conventional signs of ageing. They said 'although I look old, I feel young inside', which has an element of the denial of old age. This strategy alludes to the 'mask of ageing' notion, that people assume a distance between their external appearance and their internal, inner or subjective 'real self'. The external mask has the physical signs of ageing but creates a schism between the inner and outer selves, with the inner self remaining young (Andrews 1999; Featherstone and Wernick 1995). It also asserts the Cartesian mind/body split, a construction which has come under severe attack in many academic debates but not in studies on ageing (Andrews 1999; Gilleard and Higgs 2000). Andrews (1999) argued that this might express a way of denying old age to enable successful ageing. Some senior users seem to be influenced by these constructions. The possible consequences of such thinking are that experiences at all stages of life, particularly its later stages, lose their value in a culture that is influenced by ideals of external youthfulness and beauty. The senior users were in effect endorsing the societal and cultural prejudices of ageism. The women at the senior centre in Canada also sought to distance themselves from the category 'old' and the accompanying ageist stereotypes (Hurd 1999). They strove to establish and preserve their membership of the 'not old', but at the same time reported their fear of declining health, the realities of widowhood and the loss of their youthful attractiveness.

The seniors' negative representations of old age might be because they see themselves as consumers in a consumer society, but the ways in which they consumed differed greatly (marking the users' heterogeneity). Their disparate patterns of consumption revealed the social identities that they had developed through their lives in different contexts (Sassatelli 2007). The 'Norwegian Life-Course, Ageing and Generation Study' has shown that growing older entails experiences that change on several dimensions and which are both positive and negative. With increasing age, there is a stronger focus on the negative associations: the experienced threats are revealed with expressions exemplified by, 'as I age I have to give up many activities'. On the other hand increasing age strengthens a positive feeling of self-acceptance (Daatland, Solem and Valset 2006). Through personal experiences of the centre, some users found a way of accepting themselves and substituted their negative preconceptions with positive evaluations – the centre became a place where they liked to be. The change

exemplified an adaptive strategy to sustain health and wellbeing (Jackson 1996).

Active ageing and occupational possibilities

Some users manifested 'active ageing' through their activities at the centre. To be doing something and to feel useful were valued by both the users and the volunteers. The significance of 'feeling useful' might owe something to the oldest users' early lifecourse experiences – in the late industrial society of their youth, it was a prerequisite for an adequate sense of self. 'Using time well', being hard working, capable and self-reliant were positive ideals (Thorsen 2002). In western consumer culture, with its focus on being active, these values are promoted as strategies to postpone old age. The idea was echoed in some users' focus on 'doing something' in contrast to 'just sitting there', and also in the esteem accorded to making donations and practical contributions to the centre. Some users explained that they only managed to visit the centre once a month because they were busily occupied with other activities, such as dancing, Nordic walking, sea cruises or trips to France or America. Some volunteers also stressed the importance of doing something valuable for others as a contribution to maintaining their own fitness and activity levels. 'Active ageing' and 'productive ageing' were in these ways positively valued by the users of the centre, and were clearly associated with the senses of thriving and wellbeing. Many of their expressions affirmed the espoused benefits of 'active ageing'.

What then can we add to the critiques of active and positive ageing? Laliberte Rudman (2006) argued that positive ageing discourses are shaped in a way that limits occupational possibilities and promotes occupational injustice. Featherstone and Hepworth (1995) suggested that the positive ageing discourse creates a new form of ageism, by its high valuation of youth and beauty (see also Featherstone and Wernick 1995). The discourse influences occupational possibilities by creating ideal, possible and not-ideal occupations. Ideal occupations for 'positive ageing' include contributing to the economy as a consumer, being self-reliant and caring for one's self (*i.e.* not requiring tax-funded formal care). From this fiscal perspective, being in paid work is more honoured than occupations such as care-giving, passive and solitary leisure activities, political activism and volunteering (Laliberte Rudman 2005, 2006). Some of the users of the senior centre might have been sufficiently influenced by the positive ageing ideas to have adopted conforming behaviours, attitudes and self-constructs, for example, in their high regard for the tasks at the centre that generated income, such as managing the café and making handicrafts for sale.

Townsend and Wilcock (2004) also argued that cultural values structure people's occupational (or activity) opportunities and create occupational justice or injustices, the latter being occupational deprivation, occupational alienation (loss of meaning), occupational imbalance and anxieties around participation or non-participation (Townsend and Wilcock 2004).

Conclusions

By investigating the users of a senior centre's inter-personal experiences, it has been shown that the meanings they attach to their participation are diverse and continuously developed, contested and refreshed. The users were more or less influenced by western consumer culture's high valuation of active ageing, youth, fitness and beauty. Evidence was found that many users experienced a tension between a 'sense of thriving', which the centre's activity and social opportunities provided, and a subtler 'sense of threat', in that attendance exposed them to the inevitability of personal ageing. The study has raised understanding of the paradoxical situation that many old people face: they are encouraged to remain youthful and to embrace healthy and active ageing while, at the same time, they get older day by day. It has been shown that many of the users perceived ageing as a process that can be negotiated, resisted and denied through their interactions with the other users. The senses of community, belonging and social well-being were generated by the centre and valued, but attendance also brought them face-to-face with who they are, what they want to be, and how a person is perceived by others. This experience was variously found stabilising and destabilising but was always negotiable. At the centre they see each other. The users articulated who they *didn't* want to be in relation to others, and these expressions revealed various ways of creating distance from one's own ageing. Ageism and occupational injustice were both maintained and contested by the users in various paradoxical ways. The centre's reminders that life is not for ever raised the sense of vulnerability and the existential anxiety of growing old.

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NOTES

1 According to (Statistics Norway 2007), average female life expectancy at birth in Norway is 81.3 years, and the male figure is 76.5 years.
2 Concerning ethical issues the project is evaluated and accepted by Norwegian Social Science Data Services (NSD) and The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH).

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Appendix

Appendix 1. Overview of therapy based interventions and occupational therapy after stroke, **ICF-**International Classification of Functioning, Disability and Health**, BF**-Body Function, **A&P**-Activity &Participation, **EF**-Envrironmental Factors

Study	Design	Objective/Title	Interventions (Individual or group-based)	ICF-descriptors	Setting	Conclusion
Therapy-based						
Legg & Langhorne 2004 [1] Occupational therapy: 1. Corr 1995 2.Gilbertson 2000 3.Drummond 1995 4.Walker 1996 5.Logan 1997 6.Walker 1999 7.Parker 2001 8.Jongbloed 1991 Physio therapy: 1.Andersen 2003 2.Duncan 1998 Multidisciplinary: 1.Hui 1995 2.Smith 1981 3.Goldberg 1997(har print versjon kun) 4.Wolfe 2000	Systematic review of randomised trial: 14 trials included	Rehabilitation therapy services for stroke patients living at home: systematic review of randomised trials.	Individual interventions	Mainly BF (ADL, mobility)	Outpatients	Therapy-based rehabilitation services could be beneficial. The exact nature and content is not answered
Occupational Therapy						
Walker et al 2004[2] 1 .Jongbloed 1991 2. Corr 1995 3. Drummond 1995 4. Walker 1996 5. Logan 1997 6. Walker 1999 7. Gilbertson 2000 8. Parker 2001	Meta analysis: 8 trials included	Individual patient data meta-analysis of randomized controlled trials of community occupational therapy for stroke patients.	Individual interventions	Mainly BF also A&P (ADL, mobility, leisure)	Community based	Community occupational therapy significantly improved personal and extended activities of daily living and leisure activity. Better outcomes with targeted interventions

	Design	Objective/Title	Interventions (Individual or group-based)	ICF-descriptors	Setting	Conclusion
Steultjens et al. (2005)[3] 1.Steultjens (2003) 2.Trombley(2002) 3.Ma(2002) 4.Wilkins(2003)	Overview of Systematic reviews: 14 syst reviews included where 4 reviewed stroke.	To summarize the research evidence available from systematic reviews of the efficacy of occupational therapy for practitioners, researchers, purchasing organizations and policy makers.	Individual interventions	Mainly BF also A&P (Functional ability, participation, arm/hand function,devices, muscle tone, ADL, leisure)	Home-based	This summary shows that elderly people and people with stroke or rheumatoid arthritis can expect to benefit from comprehensive occupational therapy (includes; (1) training of sensory-motor functions; (2) training of cognitive functions; (3) training of skills such as dressing, cooking a meal, or performing domestic activities; (4) advice and instruction in the use of assistive devices; (5) provision of splints and slings; and (6) education of family and primary caregivers) Evidence of the efficacy of specific interventions is sparse and should be addressed in future research. The evidence that does exist should be incorporated into occupational therapy practice
Legg et al. (2007) [4] 1.Corr (1995) 2.Gilbertson(2000) 3.Chiu(2004) 4.Drummond(1995) 5.Walker(1996) 6.Logan(1997) 7.Walker(1999) 8.Sackley(2006) 9.Parker (2001)	Systematic review,meta-analysis: 9 trials included	To determine whether occupational therapy focused specifically on personal activities of daily living improves recovery for patients after stroke.	Individual interventions	Mainly BF also A&P (ADL, functional mobility, domiciliary occupational therapy, bathing, using devices, leisure, dressing, PADL and IADL)	Home-based (except Sackley which is at nursing homes)	Occupational therapy focused on improving personal activities of daily living after stroke can improve performance and reduce the risk of deterioration in these abilities. Focused occupational therapy should be available to everyone who has had a stroke.
McEwen et al. 2009[5]	Critical review: 26 articles included (7:general cognitiv 19: task specific)	Cognitive strategy use to enhance motor skill acquisition post-stroke: a critical review.	Individual interventions	Mainly BF (Task specific and motor-based)	Not specified	Findings suggested that general strategy training improves performance in both trained and untrained acitivities. A specific motor imagery protocol can improve mobility and recovery in the affected upper exprtremity. Further needs for development of novel cognitive strategy-based interventions

Study	Design	Objective/Title	Interventions	ICF-descriptors			Setting	Conclusion
53 identified studies related to intervention				**A&P**	**EF**	**BF**		
1 Hayner et al 2010 [6]	RCT N=12	Comparison of constraint-induced movement therapy (CIMT) and bilateral treatment of equal intensity in people with chronic upper-extremity dysfunction after cerebrovascular accident.	Individual interventions (6h for 10days).			X	Training institution	High-intensity occupational therapy using a CIMT or a bilateral approach can improve UE function in people with chronic UE dysfunction after CVA. Treatment intensity rather than restraint may be the critical therapeutic factor.
2 Stein et al 2010[7]	RCT N=30	Stochastic resonance stimulation for upper limb rehabilitation poststroke.	Individual interventions.			X	Community dwelling	No statistical differences found. Stochastic resonance therapy combined with OT was no more effective than OT alone.
3 Combs et al [8]	N=12	Effects of an intensive, task-specific rehabilitation program for individuals with chronic stroke: a case series.	Individual interventions. Task specific.			X	Ambulatory	The task specific intervention was feasible.
4 Conti et al [9]	Pilot N=3	Changes in hemiplegic grasp following distributed repetitive intervention: a case series.	Individual interventions. Grasp force			X	Community dwelling	Effect was shown among these three.
5 Unsworth et al 2009[10]	N=40	Benchmark comparison of outcomes for clients with upper-limb dysfunction after stroke using the Australian Therapy Outcome Measures for Occupational Therapy (AusTOMs-OT).	Individual interventions. Task specific.			X	Subacute unit	Further benchmarking studies are needed.
6 Lemon et al 2009 [11]	Retrospective study, Observational study. N=419, (10 were randomly selected).	Rehabilitation content and clinical stroke subtype: a small observational study.	Individual interventions. Task specific. **Physiotherapy (PT) and Occupational therapy(OT).**			X	Hospital stroke unit	There are differences in the intervention content OT and PT across the subtypes.
7 Crotty et al 2009 [12]	RCT N=26	Retraining visual processing skills to improve driving ability after stroke.	Individual interventions. Skills specific.			X		No differences shown.
8 Karges et al [13]	Non-experimental retrospective chart review n=80	A description of the outcomes, frequency, duration, and intensity of occupational, physical, and speech therapy in inpatient stroke rehabilitation.	Individual interventions **Multiprofessional**	X		X	Inpatients	Inpatient multiprofessional rehabilitation has an impact on the patients improvements.

9 Rand et al 2009[14]	N=4	Training multitasking in a virtual supermarket: a novel intervention after stroke. Mmultitask but on ONE task	Individual interventions..			X		Positive effect of Vmall.
10 Smallfield et al 2009 [15]	Retrospective chart analysis	**Classification of occupational therapy** intervention for inpatient stroke rehabilitation. Mainly prefunctional activities e.g. musculoskeletal intervention strategies individual sessions.	Individual interventions.	X		X	Inpatients	65% focussed on prefunctions 48% focussed on ADL 52% focussed on musceloskeletal interventions
11 Carin-Levy et al 2009[16]	Interviews N=14	The psychosocial effects of exercise and relaxation classes for persons surviving a stroke. **Evaluation of the participation in research**	**Group** interventions Exercise and relaxation classes	X			Community	Unexpected positive psychosocial effecxt of participating in a project offering groups with peers.
12 Tsang et al 2009[17]	RCT N=35	Occupational therapy treatment with right half-field eye-patching for patients with subacute stroke and unilateral neglect: a randomised controlled trial.	Individual interventions. Neglect: impairment level.			X	Inpatients	Right half –field eye-patching improved impairment level of unilateral neglect.
13 Sameniene et al 2008[18]	N=30	The evaluation of the rehabilitation effects on cognitive dysfunction and changes in psychomotor reactions in stroke patients.	Individual interventions Occupational therapy 5 times a week. 30 minutes for 48 days.			X	Inpatients	Significant change in the patients reaction time and movement frequency.
14 Rabadi et al 2008[19]	N=30 RCT	A pilot study of activity-based therapy in the arm motor recovery post stroke: a randomized controlled trial. Arm function/upper limb/arm ergometer or robot compared to activity based.	**Group** interventions -40 minutes of group therapy led by a certified occupational therapist.			X	Inpatients	Activity-based therapies using an arm ergometer or robot when usedd shortened training periods have the same effects as occupational therapy group therapy in decreasing impairment and improvements in the paretic arm of severely affected stroke patients in the subacute phase.
15 Nadar et al 2008[20]	Controlled quase-experimental trial n=18+18	'Show me, don't tell me'; is this a good approach for rehabilitation?	Individual interventions. Memory			X	Laboratory and community setting	Subject-performed task (SPT) and experiementel-performed task (EPT) methods are significantly more effective than receiving verbal instructions.
16 Lin et al 2008[21]	Counterbalance-repeated measure design N=26+24	Effects of task instructions and target location on reaching kinematics in people with and without cerebrovascular accident: a study of the less-affected limb.	Individual interventions. Movement of the less affected arm			X	Patients from 2 medical centres	The intervention may optimize movements.

17 Korner-Bitensky et al 2008[22]	Telephone survey of 480 OT in Canada	**A national survey of occupational therapists' practices** related to participation post-stroke.						Less than half of the occupational therapists focused interventions on leisure and social aspects of participation, suggesting a gap between what could be done to enhance successful community reintegration post-stroke and what is currently done.
18 Rand et al 2007[23]	Criterion standard n=14(stroke) n= 93(healthy)	Evaluation of virtual shopping in the VMall: comparison of post-stroke participants to healthy control groups.	Individual interventions.			X		Shopping task was challenging for stroke participants which is positive for treatment effectiveness.
19 Geusgens et al 2007[24] .	N=29	Transfer effects of a cognitive strategy training for stroke patients with apraxia	Individual interventions.			X	Rehabilitation centre and assessment in the patients home.	Patients performed trained tasks and nontrained tasks at the same level of independency at the rehabilitation centre as well as at home, indicating transfer of training effects.
20 Egan 2007[25]	RCT N=16	A pilot randomized controlled trial of community-based occupational therapy in late stroke rehabilitation. Focus was work on issues related to participation in valued activities identified by the patient.	Individual interventions. 8 visits (over 2–4 months)	X			Community based	Performance of activities were rated similar in both groups. Those in the intervention rated their satisfaction with activities significantly higher.
21 Phipps et al 2007[26]	N=155	Occupational therapy outcomes for clients with traumatic brain injury and stroke using the Canadian Occupational Performance Measure. Many clients also received outpatient services from other rehabilitation disciplines, including **physical therapy and speech therapy.**	Individual interventions. Most clients received two 45- to 90-min sessions of outpatient occupational therapy per week for 4–12 weeks.	X			Outpatient	This study found that a statistically and clinically significant change in self-perceived performance and satisfaction with tasks of daily life occurred at the end of a client-centered occupational therapy program ($p < .001$).
22 Page et al 2007[27]	N=4	Mental practice as a gateway to modified constraint-induced movement therapy: a promising combination to improve function.	Individual interventions ADL and mental practice	X		X	Outpatient is written and also the same environment	Data suggests positive features of mental practice.
23 Black et al 2006[28]		How **occupational therapists and physiotherapists** can help stroke patients recover	Only a description and not any studies					
24 Sackley et al 2006[29]	Cluster RCT n=118	Cluster randomized pilot controlled trial of an occupational therapy intervention for residents with stroke in UK care homes.	Individual interventions.	X			Nursing home residents	Those who received occupational therapy were less likely to detoriate.

25 Latham et al 2006[30]	N=954	Occupational therapy activities and intervention techniques for clients with stroke in six rehabilitation hospitals.	Individual interventions. Upper-extremity control and basic activities of daily living .	X		X	Patients at hospital	Occupational therapy provided an integration of treatment approaches. A small proportion of sessions addressed community integration
26 Beckley 2006 [31]	N=95	Community participation following cerebrovascular accident: impact of the buffering model of social support. The purpose of this study was to examine the impact of the buffering model of social support on stroke outcomes.	Individual interventions.	X		X	Community based (in the homes)	The importance of social support is addressed. Intervention practices in rehabilitation programs will need to go beyond traditional clinical training and extend the focus of treatment to practices that foster social support and community participation. In addition, future rehabilitation studies would benefit from a focus on social support needs in discharge planning.
27 Pang et al 2006[32]	RCT N=63	A community-based upper-extremity group exercise program improves motor function and performance of functional activities in chronic stroke: a randomized controlled trial.	**Group** intervention			X	Community-based	The community based exercise program can improve upper extremity function.
28 Richards et al 2005[33]	N=713 who received treatment	Characterizing occupational therapy practice in stroke rehabilitation.	Individual interventions.	X			Inpatients	Little time was spent on leisure and community reintegration. More higher level activitites was related to greater success.
29 Turton et al 2005[34]	RCT n=25	A pilot randomized controlled trial of a daily muscle stretch regime to prevent contractures in the arm after stroke.	Individual interventions.			X	Rehabilitaion ward	No significant effect found
30 Lynch et al 2005[35]	RCT N=280	Continuous passive motion improves shoulder joint integrity following stroke.	Individual interventions.			X	Stroke unit	Positive trends, but no significant difference.
31 Desrosiers et al 2005[36]	RCT N=41	Effectiveness of unilateral and symmetrical bilateral task training for arm during the subacute phase after stroke: a randomized controlled trial.	Individual interventions.			X	Rehabilitation unit - inpatients	No significant differences between the groups.
32 Suzuki et al 2005[37]	N=256	**Incidence and consequence of falls** in inpatient rehabilitation of stroke patients.				X	Inpatients	
33 Carey et al 2005[38]	Single case experiments N=10	Training of somatosensory discrimination after stroke: facilitation of stimulus generalization . Repeated presentation of targeted discrimination tasks -progression from easy to difficult	Individual interventions.			X	Inpatients	Generalization of training within a somatosensory modality poststroke, provided that a program designed to enhance transfer is used. This has implications for the design of efficient rehabilitation programs.

34 Kluding et al 2005[39]	N=24 9 completed all testing	Exercise-induced changes of the upper extremity in chronic stroke survivors	Individual interventions. 36 sessions From ***physio*** department			X	Not specified	Aerobic capacity can improve but further studies ar required
35 Rimmer et al 2005[40]	Literature study	Aerobic exercise training in stroke survivors.	Individual interventions.			X	Not specified	Specific recommendations for aerobic training must become more precise
36 Logan et al 2004[41]	RCT n=168	Randomised controlled trial of an occupational therapy intervention to increase outdoor mobility after stroke.	Individual interventions.	X		X	Community setting	A brief intervention by an occupational therapist improves outdoor mobility in community dwelling people after stroke. The intervention includes the provision of information, aids, and appliances, and approaches to overcoming fear.
37 Koski et al 2004[42]	Evalauation of assessment tool. N=10	Immediate and long-term changes in corticomotor output in response to rehabilitation: correlation with functional improvements in chronic stroke.	Individual interventions. (hemiparetic arm)			X	Inpatients	Evaluation of TMS which seemed to be useful (transcranial magnetic stimulation)
38 Liu et al 2004[43]	Prospective RCT N=46	Mental imagery for promoting relearning for people after stroke: a randomized controlled trial.	Individual interventions.				Inpatients	Mental imagery can promote relearning of daily tasks
39 Tsuji et al 2004[44]	Structure analysis N=107	Physical fitness in persons with hemiparetic stroke: its structure and longitudinal changes during an inpatient rehabilitation programe.	Individual interventions. -80min each day. **Physiotherapy and occupational therapy** daily			X	Inpatients	Structure of fitness was confirmed and PCA scores were useful
40 Diener et al 2004[45]	An individual is assessed	Determining decision-making capacity in individuals with severe communication impairments after stroke: the role of augmentative-alternative communication (AAC).	Individual intervention Impairment **Speech-language pathologist and occupational therapist**			X	Nursing home	Alternative equipment became means to further explore complex medical decisions
41 Moreland et al 2003[46]	RCT N=68+65	Progressive resistance strengthening exercises after stroke: a single-blind randomized controlled trial.	Individual intervention. **Physiotherapy**			X	Inpatients	Progressive resistance exercise, versus the same exercises without added resistance, did not affect common clinical measures of gross motor function and walking in stroke patients undergoing inpatient rehabilitation. As reported by other studies, there were no detrimental effects on muscle tone from resistance training.

42 Gillot et al 2003[47]	N=2	Perceptions and experiences of two survivors of stroke who participated in constraint-induced movement therapy (CIMT) home programs.	Individual interventions			X	Home-based	CIMT helped to be more satisfied with performance.
43 Rodrigue et al 2003[48]	Literature search	Meeting the nutritional needs of patients with severe dysphagia following a stroke: an interdisciplinary approach.	Individual interventions **Interdisciplinary**			X	Inpatients	Dysphagi present in 44% of stroke population and 69% had mild to moderate stroke severity deficit
44 MacKay et al 2002[49]	Descriptive, longitudinel	Cardiovascular stress during a contemporary stroke rehabilitation program: is the intensity adequate to induce a training effect?	Individual interventions **Occupational therapy and physiotherapy**			X	Inpatients-stroke unit	The physiotherapy and occupational therapy sessions did not elicit adequate cardiovascular stress to induce a trainging effect
45 Turton et al 2002[50]	Literature study	When should upper limb function be trained after stroke? Evidence for and against early intervention. Considers the physiology of the brain in acute stroke	Individual interventions.			X	Acute phase	This review has highlighted the paucity of clinical research in examining the optimal time of intensive arm training for recovery of hand function after stroke. More research is clearly needed to answer our question. Physical therapy in the first few days after stroke should be given in the context of optimum physiological basic care and should not undermine these onsiderations.
46 Andersen et al 2001 [51]	Litt review 16 RCT	[Intervention for apoplexy patients discharged from hospital. Physical training: a literature review*) Danish*	Individual interventions.			X	Home-based	Continued rehab after discharge is important. Home-besed is effective. ESD can reduce hospital stay Further evaluations are needed.
47 Parker et al 2001[52]	RCT n=466	A multicentre randomized controlled trial of leisure therapy and conventional occupational therapy after stroke. TOTAL Study Group. Trial of Occupational Therapy and Leisure.(in UK)	Individual interventions. Mood, leisure and ADL	X		X	Home-based	In contrast to the findings of previous smaller trials, neither of the additional OT treatments showed a clear beneficial effect on mood, leisure activity or independence in ADL measured at 6 or 12 months.
48 van Heugten et al 2000[53]	N=33	Rehabilitation of stroke patients with apraxia: the role of additional cognitive and motor impairments.	Individual interventions. Apraxia			X	Inpatient	Apraxia is associated with additional cognitve and motor impairment
49 Edmans et al 2000[54]	RCT N=80	A comparison of two approaches in the treatment of perceptual problems after stroke.	Individual interventions. Perception			X	Inpatient	No significant differences

50 Volpe et al 2000[55]	RCT N=56	A novel approach to stroke rehabilitation: robot-aided sensorimotor stimulation.	Individual interventions. Robot training.			X	Inpatient	Intervention group showed improvements.
51 Gilbertsen et al 2000[56]	RCT n=138	Domiciliary occupational therapy for patients with stroke discharged from hospital: randomised controlled trial.	Individual interventions At home Domiciliary occupational therapy	X		X	Inpatients	The functional outcome and satisfaction of patients with stroke can be improved by a brief occupational therapy progr4amme after discharge. Major benefits may not, however be sustained.
52 Green et al 2007 [57] *(included in the group intervention overview in appendix 2)*	RCT N=200	Education in stroke prevention: efficacy of an educational counselling intervention to increase knowledge in stroke survivors. Lifestyle classes and interviews were applied.	Group interventions **Nursing**	X			Community based -ambulatory -outpatient clinic	It is possbible to improve knowledge and initiate lifestyle change
53 Sit et al 2007[58] *(included in the group intervention overview in appendix 2)*	Quasi experiemental design. N=190	A quasi-experimental study on a community-based stroke prevention programme for clients with minor stroke.	Group interventions **Nursing**	X			Community based	Education helped tha stroke participants to integrate their learned knowledge in their real lives

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Appendix 2 Community-based group interventions for older adults after stroke, CG=Control group, IG=Intervention group

Study	Design	Participants	Age	Intervention content/focus	Duration	Group leaders	Outcome meaures	Conclusion
AUSTRALIA								
Kendall et al 2007[1]	RCT	Total n=100 CG;n=42 IG; n=58	65 (25-82)	CG; standard rehab. care IG; standard care AND course in groups. Self-management such as; education,engagement in activities to promote health and well-being, adopting healthy behaviour, minimise negative influence of their illness, manage negative impact, take an active role in their own health by developing partnership with health professionals.	7 weeks (2h a week)	Trained health professionals	-Stroke Specific Quality of Life Scale(SSQOL) -Self-Efficacy Scale	CG reported decline during the first year. IG avoided decline. The intervention failed to influence mood, thinking, social roles and self-efficacy which was unexpected. It is possible that merely being offered an intervention, being exposed to other participants, knowing that ongoing group support is available may be sufficient.
Marsden et al 2010[2]	RCT, -pilot, cross over design	Total n=42 n=25 stroke survivors n=17 careers	70/73	Rural settings for community-dwelling chronic stroke survivors and their carers. To measure the impact of the programme on health-related quality of life and functional performance; and to determine if any benefits gained are maintained. This novel programme incorporated physical activity, education and social interaction	7 weeks (1h a week)	Multidisciplinary	-Stroke Impact Scale -Health Impact Scale -Six Minute Walk test -TUG -Caregiver Strain Index	This programme may improve and maintain health-related quality of life and physical functioning for chronic stroke survivors and their carers and warrants further investigation. Insufficient participants to reach statistical significance.
Cadilhac et al 2011[3]	RCT	Total n=143 Three groups: **I.** n=48,Stroke Self-Management Program(SSMP) **II**:n=47,Generic,Self-Management program Stanford **III.**n=48Control/ standard care	69	Self-management program **I.** SSMP;only stroke survivors, 8 weeks AND standard care **II**.Stanford generic intervention, 6 weeks AND standard care **III**. Standard care/control-information(education offered at the hospital)	8 weeks (2.5h a week)	SSMP –health professionals and peer leader trained in stroke	-Participation rates -Completion rates -Positive and active engagement in life(1-6) -Health Education Impact Questionnaire -Mood (irritability, depression and anxiety -Self-reported diary	SSMP was safe and feasible. Benefits of the stroke specific program over the generic included greater participation and completion rates. An efficacy trial is warranted. ANCOVA showed no statistically differences between groups but in "on-program analysys the CohenD showed significant effect of SSMP

CANADA								
Huijbregts et al 2008 [4]	RCT and Focu groups	Total n=30 CG;n=12 IG; n=18	68 (42-82)	Compared two group programs. I Living With Stroke(LWS) and II Moving On after STRoke (MOST). **LWS** is stnadard care in Canada;educational program, prescribed with manuals, video clips and information booklets in 8 themes. **MOST** is a self-management program based on self-efficacy theory Bandura social cognitive theory. Used land exercise and pool program. In both programs the psycho social part was addressed.	CG; LWS,6 weeks (90min a week) IG; MOST,8 weeks,2 h twice a week.1 booster session after 6 weeks	Trained health professionals Physio assistant and volunteers supported in the exercise programs	-Reintegration to normal living -Activity soecific Balance Scale -FIM -Geriatric Depression Scale -Activity Inventory of the Chedoke McMaster Stroke Assessment	MOST is more expensive but however recommended. Improvements in both groups but no sig between group differences (ANCOVA). The social benefits of group exercises may be more important than physical benefits. The importance of psycho social factors is emerging here
Green et al 2007[5]	RCT	N=200	66/67	Education in stroke prevention: efficacy of an educational counselling intervention to increase knowledge in stroke survivors. IG; Lifestyle groups/classes combined with individual motivational interviews. The lifestyle class had 50-75 participants Used SMART, Motivational interviews	1 interview and after 1/2mnth a lifeatyle-class	Nurses Lifestyle class was also with nutritionist, and social worker	-Stroke knowledge questionnaire	Significant diff erences were found between groups on stroke knowledge.No significant differences between groups on identified risk factors.It is possbible to improve knowledge and initial lifestyle
CHINA								
Sit et al 2007[6]	Quasi experie mental design	Total n=190 IG,n=77 CG,n=70	62/64	Study on a community-based stroke prevention programme for clients with minor stroke. IG; Conventional medical care AND Classes/groups and 8 fixed educational themes CG: Conventional medical care	8 weeks (2 h a week)	Nurses	-Stroke knowledge questionnaire -Self-health-monitoring practice	Education helped the stroke participants to integrate their learned knowledge in their real lives.Positive statistic significant effects on knowledge, initiation of risk reduction behaviours, establishment of self BP monitoring and healthy dietary habits

UNITED KINGDOM								
Mead et al 2007[7]	RCT	Total n=66 IG:Exercise;n=32 CG:Relaxation;n=34	72	Stroke: A Randomized Trial of Exercise or Relaxation. Transport offered Exerc.:1h 15 incl tea and chat Relax: 20min-49m	12 weeks (3xweek for both interventions)	Advanced exercise instructor in both interventions	-FIM -Nottingham Extended ADL -Rivermead Mobility Index -functional reach, -sit-to-stand -elderly mobility score -SF-36v2 -HADS -TUG	Exercise training for ambulatory stroke patients was feasible and led to significantly greater benefits in aspects of physical function and perceived effect of physical health on daily life. **3m:** role physical, TUG, walking economy were sig better in exercise. **7m:** Role-physical was the only significant difference between the groups
Harrington et al 2010[8]	RCT	Total n=243 CG,n=124 IG,n=119	70/71	A community-based exercise and education scheme for stroke survivors: a randomized controlled trial and economic evaluation CG: standard care, info about local groups and contact persons. Visit 6 weeks after discharge IG; 1hour exerc and 1h interactive education. Content from previous programs. Carers were encouraged to participate Leisure and community centres	8 weeks (twice a week,2h)	Invited speakers eg stroke coordinater,local stroke association manager, diettician. Volunteers helped and were trained by a health psychologist	- Subjective Index of Physical and Social Outcome (particularly for stroke), -FIM, -Rivermead - TUG - WHOQOL - HADS	There were significant between-group changes in SIPSO physical at nine weeks and at one year and (only) WHOQol-Bref psychological at six months. Mean cost per patient was higher in the intervention group. The difference, excluding inpatient care, was £296 (95% CI: –£321 to £913). Conclusion: The community scheme for stroke survivors was a low-cost intervention successful in improving physical integration, maintained at one year, when compared with standard care. No statistically significant differences between the groups on HADS, TUG,and the other outcome measures

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Oslo universitetssykehus

HELSE SØR-ØST

MONITORING CERTIFICATE

Study title: Well-being, activities and social participation after stroke/TIA. A randomized controlled trial.

(Norwegian: Trivsel, aktivitet og sosial deltagelse etter hjerneslag. Psykososial rehabilitering i eldresenter av personer med lette til moderate hjerneslag. En randomisert kontrollert undersøkelse)

Principal investigator: Anne Lund

It hereby confirms that a database monitoring of the following questionnaire is completed in approximately 20% of study participants:

- SF-36 Health Survey
- The Canadian Occupational Performance Measure (COPM)
- The Timed Up and Go (TUG)
- Trail Making Test A and B
- Ullevål afasi screening

Monitoring is performed by:

Oslo, 17. februar 2011
Place and date

Irene Syse
Irene Syse

Oslo universitetssykehus HF, Ullevål
Seksjon for GCP

Seksjon for forskningsadministrasjon, Enhet for klinisk forskningsstøtte